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WHAT RESEARCHERS ARE PUBLISHING

AND

WHAT PARENTS ARE IMPLEMENTING

CURRENT INTERVENTIONS FOR AUTISM

A Research Project submitted in partial fulfillment of the requirements for the degree of

MASTER OF EDUCATION

To the faculty of the department of

EDUCATION

At

LYNN UNIVERSITY

Boca Raton, Florida

By

Barrie Tripp

SUBMITTED

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APPROVED

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CHAPTER ONE

According to the Autism Society of America, one in 500 children will be diagnosed with a disability that is designated as Autism Spectrum Disorder (Center for Disease Control and Prevention, 1997). The disabilities that fall under this spectrum are: Autistic Disorder, Asperger's Disorder, Pervasive Developmental Disorder -Not Otherwise Specified, Rett's Disorder and Childhood Disintegrative Disorder (<http://www.Autism-society.org/Autism.html>). These disabilities are complex, life-long disorders that usually appear during the first three years of a child's life. These disorders affect the child's understanding of social interactions, the ability to communicate and the ability to enjoy leisure activities. In some cases self-injurious behavior will also be present.

Each of the above disorders differ from one another because of their individual characteristics. A child with Autistic disorder will show "severe and pervasive impairment in several areas of development: reciprocal social interaction skills, communication skills, or the presence of stereotyped behavior interests, and activities" (APA 1994, pg65). Asperger's Disorder is characterized by impairments in social interaction and the presence of restricted interests and activities, with no clinically significant delay in language, and testing in the range of average to above-average intelligence. Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS) is commonly referred to as atypical Autism. A diagnosis of PDD-NOS, may be given when a child does not meet the criteria for a specific diagnosis, but there is severe and pervasive impairment in specified behaviors. Rett's Disorder is a progressive disorder which, to date, has occurred only in girls. It is characterized by a period of normal development and then, loss of previously acquired skills, loss of purposeful use of the hands, replaced with repetitive hand movements, beginning at the age of one to four years. Childhood Disintegrative

disorder is characterized by normal development for at least two years, with significant loss of previously acquired skills. (<http://www.Autism-society.org/autisin.html>).

There are other disorders that are very similar to the Autistic Spectrum Disorder, but are not classified as such. One of those disorders is called Landau-Kleffner syndrome. This syndrome is classified as "loss of language after a period of normal development, usually of more than two years and sometimes as long as seven years" (Cohen, 1988, pg. 14). This disorder can often be helped with medication, which is a significant difference from Autism spectrum disorder. Another similar disorder is Obsessive-Compulsive Disorder. The rituals and fixed routines associated with OCD are very common to those displayed by children with the Autistic spectrum disorder (Ibid. pg. 17). Finally, a genetic disorder known as Fragile X syndrome is commonly misdiagnosed as Autism. With Fragile X, however, there is usually no difference in treatment. One would treat Fragile X the same as treating a child with Autism.

As every child is different, those who are diagnosed with these disabilities are different from each other. The symptoms that the child can present range from mild to severe impairment. As with many disabilities, the causes of Autism are not known. Currently, there are no proven medications for Autism. Research, conducted, recently, has ruled out commonly thought theories that it is a mental illness, caused by bad parenting, or that the child just chooses to misbehave. What has been found, is that Autism Spectrum Disorder does affect boys four times more often than girls, and that there may be a genetic link, as Autism does run in families (Cohen, 1998). Since children differ so drastically from each other, it has been very hard to find one common method that will help all children with Autism or Autism Spectrum Disorder.

There are many different treatment options for children with Autism. Some of the therapies used are Auditory Training, Sensory Integration Therapy, Holding Therapy, The

Lovaas Method, and The Treatment and Education. of Autistic and Related Communication Handicapped Children", more commonly known as TEACCH (<http://www.Autism-society.org>).

Descriptions of the main education treatments are as follows:

LOOVAS METHOD

" The Loovas Method", is, otherwise, known as Applied Behavioral Analysis (ABA). Dr. Lovaas, who used this method in the treatment of Autistic children, published a paper in 1987. This began to change the field of Autism treatment practices across the country. His study involved extensive treatment for 38 children who were younger than 40 months of age, or 46 months of age, if they were echolalic (parroting back speech). Dr. Lovaas (1998) found that those who received 40 hours a week of one-to-one treatment, for at least two years, made significant gains in functioning.

Loovas Therapy employs methods of scientific principles of behavior to build socially useful repertoires and reduce problematic ones. (Green, 1996, pg. 29). This therapy is based in the home and usually administered by trained family members, students, and volunteers. The first step, in setting up this type of therapeutic intervention, is the training of those who have been employed by the family, to work with the child. Representatives of The Loovas Institute for Early Intervention, run by Dr. Loovas, will come to a family's home and conduct, what they call, a three-day workshop. According to Dr. Loovas, it is essential that the three-day initial workshops be scheduled in order to help reduce the confusion that parents may experience when being confronted with an altogether new way of handling their children, with a variety of programs. During these three days, the family and their staff are taught how to begin their child's treatment, including instructions about the clinic's teaching procedures, what to teach and when to teach it, how to keep records, how to supervise staff, and how to analyze problems in a child's

learning. The majority of the time, however, is devoted to working one-on-one with the child.

The workshop leader models teaching procedures, and the family and staff copy these procedures and receive feedback (Loovas, pg. 244).

What they will be teaching the family, according to the literature received from The Loovas Institute for Early Intervention, is a theory based on creating success for the child. They believe that children with Autism have failed to learn through typical channels. Since they have failed before, it is imperative to set up teaching situations that will maximize the child's success and minimize their failures. As a part of their teaching and therapy, they accomplish this with the simplification of requests, providing prompts for the child when needed, and providing extensive reinforcement for socially appropriate behaviors. Examples of these methods would be the use of a small bite of a favorite food when a desired activity is performed. When a student progresses, these types of reinforcements are faded and replaced with more common social everyday reinforcements. They state that, "intervention is structured so that 'positive' behaviors are maximized through prompting and positive reinforcement. High rates of aggressive and/or self-stimulatory behaviors are reduced by being ignored and by teaching alternate, more socially acceptable forms of behavior". (<http://www.Loovas.com>). This is all in the first phase of teaching a child with Autism. Depending on the skill level of the child, examples of the different programs are as follows.

Beginning Programs

Attending Skills

- Sits in a chair independently
- Makes eye contact in response to name
- Makes eye contact with given the instruction "Look At Me"
- Responds to the direction "Hands Down"

Imitation Skills

- Imitates gross motor movements
- Imitates actions with objects
- Imitates fine motor movements
- Imitates oral motor movements

Receptive Language Skills

- Follows one-step instructions
- Identifies body parts
- Identifies objects
- Identifies pictures
- Points to pictures in a book
- Identifies objects by functions

Expressive Language Skills

- Points to desired item in response to "What do you want?"
- Verbally requests desired items
- Labels objects
- Labels pictures
- Makes a choice
- Answers social questions
- Labels possession

Pre-Academic Skills

- Matches - identical objects, objects to pictures, colors, shapes, letters, numbers
- Counts by rote to 10
- Identifies Colors
- Identifies Shapes
- Identifies letters
- Identifies numbers
- Counts objects

Intermediate Programs

Attending Skills

- Sustains eye contact for 5 seconds in response to name
- Asks “What” when name is called
- Makes eye contact in response to name while playing

Imitation Skills

- Copies simple drawings
- Imitates block patterns
- Imitates sequenced actions with objects
- Imitates actions with paired sounds.

Receptive Language Skills

- Identifies emotions
- Identifies rooms
- Pretends
- Gives two objects
- Labels categories
- Identifies gender
- Follows directions with prepositions

Expressive Language Skills

- Imitates two and three word phrases
- Requests desired item in a sentence in response to “What do you want?”
- Labels objects based on function
- Labels emotions
- Uses simple sentences
- Reciprocates Information such as “I see a ...”
- Labels pronouns
- Answers Where questions
- Names what belongs in rooms
- Labels function of rooms

Pre-Academic Skills

- Completes simple worksheets
- Copies letters and numbers
- Identifies written name
- Writes name
- Pastes and Glues
- Cuts with scissors
- Color within a boundary.

At this stage another area is added to the curriculum. This area is self-help Skills that at this stage would involve:

- Puts on Pants
- Self-initiates for bathroom
- Is toilet-trained for bowel movements
- Washes hands
- Puts on coat. (Taylor & McDonough pg. 66 - 67).

It is also encouraged that follow-up workshops take place, with the family and therapists, typically, after the first month, and then, every three to four months, thereafter. This is to provide the family with updates on the child's progress, well as updating the goals for the child, should he or she master them.

Once basic tasks are mastered the next phase of intervention is started. This portion of the intervention emphasizes the teaching of expressive and early abstract language, and interactive play with peers. In the more advanced stages of their intervention. some of these skills are taught: pre-academic skills, social skills, teaching the child to learn by observing how other children learn.

Examples of the more advanced stages of the Loovas method curriculum would include the following skills to be taught.

Attending Skills

- Makes eye contact during conversation
- Makes eye contact during group instruction

Imitation Skills

- Imitates complex sequences
- Imitates peer play

Receptive Language Skills

- Follows three step instructions
- Names a person, place or thing when it is described
- Identifies items that are the same
- Identifies items that are different

Expressive Language Skills

- States "I don't know to unfamiliar questions
- Names items in a category
- Retells a story
- Tells own story
- Asserts knowledge

Abstract Language

- Answers "Why....?" Questions
- Makes logical completion's to sentences
- Predicts outcomes
- Provides explanations
- Takes another perspective
- Identifies main topic in story and conversation

Academic skills

- Completes a pattern
- Names letters sounds
- Names a word beginning with letter sound
- Makes initial, medial and final consonants
- Spells Simple words

Social Skills

- Imitates actions of a peer
- Follows directions from a peer
- Asks peer for assistance
- Offers assistance to a peer
- Plays board games with a peer

Self-help Skills

- Zippers
- Buttons
- Snaps
- Brushes Teeth

(Taylor & McDonough pg. 66 - 67)

All of the beginning stages of therapy are taught at home, in a one-to-one teaching manner. Therapy should be for five to seven hours per day for five to seven days per week (<http://206.170.81.244/services.htm>). While this may seem like an extensive period for a child, these sessions are broken down, significantly. The day is broken down into sessions of two to three hours in length. In those sessions, teaching is usually for five to seven minutes at a time, then followed by a short break for the child. Time is calculated for the child to go and play outside, as that is also an essential skill that the child needs to learn as well (<http://206.170.81.244/services.htm>).

In this type of therapy, inclusion is often suggested after a period of successful therapy at home. Once the child has progressed to a certain level of functioning, it is now critical for the child to be around 'typical' children. He or she needs to learn how to interact, appropriately. The only way for him to learn certain social skills is to participate in as many activities with typical children, as possible. His level of functioning will dictate the best environment for him, but typically an aide goes with the child in the beginning, and then fades out as the child learns the

routines of the classroom, and can initiate interaction with his peers

(<http://www.206.170.81.244/services.htm>).

It should be noted that this type of therapy is usually paid for entirely by the family. The cost of a workshop from the Loovas Institute, recruitment and pay of therapists, as well as supplies and materials, can be quite expensive. According to different estimates, an effective home therapy program can cost anywhere from \$20,000 - \$40,000 per year (Harris & Weiss, 1998 pg.72). Very few school districts will pick up the cost of these programs. In certain instances, the school districts will fund portions of the home program, if they do not have a program currently in place for a child with Autism. Few health insurance companies pay the cost of the above therapy, nor will they pay for services such as speech, occupational or physical therapy for children who have Autism.

TEAACH

Treatment and Education of Autistic and related Communication Handicapped Children, more commonly known as TEAACH, is another therapy that is used for the treatment of Autism and the Spectrum Disorders. This program was developed in the early 1970's as a public health program in North Carolina. The founder of the program was Eric Schopler, who was its director until 1994. According to the home page for project TEAACH their approach focuses. "on the person with Autism and the development of a program around this person's skills, interests, and needs". This program never claims to "cure" Autism, but teachers work with the children. The major priorities include "centering on the individual, understanding Autism, adopting appropriate adaptations, and a broadly based intervention strategy building on existing skills and interests" (<http://www.unc.edu/depts/teaach/whatis.htm>). Their focus is taking what the child has and building on it, while focusing on the child's interests. One way that they differ from

Loovas is that they do not recommend a set number of hours per day that the student be engaged in direct instruction.

When implementing a TEAACH program, there are many components that must be included. Some of these common attributes are respect for Autistic people. Those working with the Autistic child must have respect for the parent, and be able to treat the parents as co-therapists (<http://www.unc.edu/depts.teaach/teacchn.htm>). Parents should be included in the making of decisions regarding the child's treatment. Those with Autism should participate in inclusion to the maximum extent possible. Additionally, those treating the children should be warm and caring professionals, and should have an in-depth knowledge of Autism from all points of view including medical, educational and social mainstreaming. In addition to these common attributes of a TEAACH program, the program itself will be continuously evolving. As new teaching techniques are developed and evaluated, they should be implemented. A comprehensive TEAACH program will start at a very early age and stay with the child until adulthood, and be evolving as the child makes progress. (<http://www.unc.edu/depts/teacchn.htm>). While these are all attributes of a TEAACH program, it should be stated that TEAACH is not one teaching style or program. It is a multitude of programs best suited for the child. The major difference between Loovas and TEAACH is that TEAACH uses many approaches and tries to use what will work best for the individual child.

TEAACH's main goal, as stated in their program statement is, "To help Autistic children grow up to a maximum autonomy at adult age" (<http://www.unc.edu/depts/teacchn.htm>)

When a child is first introduced into the TEAACH program, he or she is thoroughly assessed to see what skills he or she currently has. The assessment that the TEAACH program commonly uses is called the PEP-R. This stands for "Psycho Educational Profile-Revised". This particular

test is divided into different domains, which are Imitation, Perception, Fine Motor Skills, Gross Motor Skills, Eye-Hand Integration, and Cognitive Performance. Eric Schopler, Margaret Lansing, and Robert Reichler (1976) developed this assessment. The results for these tests are based on a pass, not pass, ideal. When a skill is assessed the student will either have the skill, not have the skill, or the skill is emerging. Based on the results of the assessment, the child's educational plan is then developed. Another aspect that makes TEAACH different from Loovas, is the TEAACH method does not address behavior directly, it examines its underlying causes. They believe that reducing the child's environment, and making it predictable, will reduce the problem behavior. As the child makes progress, the teachers can slowly reintroduce complexity into his/her environment. They also feel by providing different ways for the child to communicate, problem behaviors will be reduced. One common element used in a TEAACH program is a visual picture system called Picture Exchange Communication System (PECS) for communication. PECS is commonly found in classrooms where TEAACH is used because it is a relatively easy way to teach an Autistic child to communicate.

Another characteristic of the TEAACH program is structured teaching. This is a very important component. The TEAACH view of structured teaching begins with the physical environment of the classroom. The TEAACH program encourages simple, no distraction, classroom set-ups. Many students with Autism are distracted easily and have difficulty with directions. If the classroom set up is complicated they will not be able to get from one area to the next. If the classroom is set up with lots of distractions, the Autistic child might not be able to tend to his/her work. One of the common items, they say to look for, is a classroom located near a bathroom if the child is learning toilet training. We do not want to discourage him/her by

having an accident. If he or she had to go far, and if a child is already toilet trained, we do want to waste valuable teaching time trekking to the bathroom.

The age of the children also affects where the classroom should be located. If you were teaching children who were older, you would not want your classroom to be placed on a floor with kindergarten children because that does not provide for peer socialization activities. Once the classroom location has been determined, the physical classroom environment must then be developed. A classroom with lower functioning students will have a high degree of structure and boundaries. Students who are higher functioning will have an environment in less structure and have fewer boundaries.

After the environment has been set up appropriately, TEAACH recommends the development of class schedules, and a individual schedule for the children enrolled in the class. This can be difficult because some children may need one-on-one assistance for some activities, and others may not. An example of a typical middle school class schedule is as follows:

8:30	Student arrival put belongings away, greetings
8:45	Work session 1
9:30	Work session 2
10:00	15 minute break
10:30	Leisure leaning/school friends
11:00	Work session 3
11:45	Prepare for lunch
12:00	Lunch
12:30	Outside/gym
1:00	clean cafeteria tables and floors
1:45	Work session 4
2:30	Dismissal

(<http://www.unc.edu/depts/teacch/structur.htm>).

This schedule addresses the overall classroom routine. Each student during work sessions would be engaged in different activities. Examples of these different sessions could be independent prevocational work, and individual training of self-help skills. Usually in a

TEACH classroom, the class schedule is posted somewhere in the classroom, where all students can use it. Some students may not be able to understand a written schedule so teachers are encouraged to use pictures, along with the activities, so that all can understand the general classroom routine.

Along with the classroom schedule, a student schedule is also developed. It must have a combination of difficult and successful activities for the children. The development of their schedule is based on the students' level of comprehension and endurance. The most important aspect of the student schedule is that it is based on the students themselves, and that they understand the schedule, and what to do in each of the areas in which they are working. A few examples of how schedules are developed and implemented in the classroom are found at the web site <http://www.unc.edu/depts/teacch/structur.htm>.

Schedule I

"-Tacked to the bulletin board beside a student's work area are rows of 4-5 Polaroid pictures for each work session. The student starts with the topmost picture and gets materials needed, completes the activity and puts his materials away. He continues following this schedule through all the pictures for a work session. The last picture in each row is of a game or toy that the student likes. When he reaches that picture, he can play with the toy until the bell rings for the next work session to begin".

Schedule II

"-Taped to a student's desk is a piece of paper divided into 3 rows of 3 squares each. Each square has a drawing or a list of numbers in it. Each square corresponds to a time block of the general classroom schedule. The student follows the schedule from left to right. The first block lists numbers of the tasks he is to do independently in the workshop area. At the signal which ends the first work period, he follows directions in the second box which shows a drawing of a table and chair representing individual work with a teacher. The third block has a drawing of the break area. The student continues following the schedule throughout the day. This student receives money upon successfully completing or attempting all the activities listed or drawn in each block. He spends his money at snack and at the end of the day for edibles or inexpensive treats like stick-ons."

Schedule III

“-After arriving, a student puts away his personal belongings and picks up his clipboard which is hanging on the wall. On the clipboard is a time schedule, which includes all his activities for the day, each, followed by a small box for a checkmark. The teacher and student wrote the schedule together at the end of the previous day. He sees what his 8:30 activity is and does it to completion. He then calls the teacher to check his work and receives a checkmark in the box on his schedule. His next task is scheduled at 8:50. If there is time remaining he may spend it quietly in the leisure area. He proceeds through the day by referring to his schedule and the clock. He does not receive checkmarks if he does not finish a task in the allotted time or with appropriate behavior. Receiving a certain number of checkmarks results in a star on a chart at the end of the day. Four stars during the week leads to his choice of free time activity instead of work on Friday afternoon”.

These schedules are a fundamental component to teaching students using the TEAACH method and structured teaching. Another component of structured teaching is the way you actually teach the class, when they are in large groups. One method, that they advocate, is what is known as "Layered Group" teaching. Layered Group teaching begins with all students starting out in a group. The teacher begins with the entire class doing an activity in which all students are able to participate. Once that activity is over; you send the student or students who are unable to complete the next circle time activity to various stations. At these stations, the students could be working one on one with a speech therapist, or working completely independently. At the original circle, the teacher has 5 students who are able to complete more advanced circle time activities. At the end of the next group of circle time activities, she/he again sends those who cannot complete the activities to stations in which they can participate. At that time, the teacher might also have the original 3 sent to other activities, switch activities. At this point, she/he has 2 students who are left in the original circle. The teacher would do the most complex activities with these two, and when that activity is finished, he/she would have the final two start their

rotations. An example from the web site <http://www.unc.edu/depts/teacch/class.htm> outlines this type of class.

"LAYERED GROUP": As in mathematics, remember to start with "lowest common denominator.

" GROUP TIME may begin with a circle that includes the entire class. As the group activities progress, they will likely include greater language demands, and become less concrete. Students with Autism should only be expected to stay in the group for the activities that are appropriate for their developmental and language level. Do these activities first. GROUP TIME will actually consist of one, two, or even three discreet groups. For example, after morning songs, direct the child who can handle only a short group to her next activity. This is an ideal time for that student to have an independent work session. After the next level of activities that might include calendar, weather, etc., do the same. The children remaining in the group for the more abstract language focused activities are those who have a higher level of language and conversational skills." As you can see from this example, the program is very individualized to the skills of the child. It also allows for those who are higher functioning within the opportunity to participate more by moving those who are not capable to other areas.

School or Centered based program

In addition to the therapy types discussed previously, there are different types of thereuptic approaches that are taken in a school or centered-based program. Usually, they incorporate various aspects of either the Loovas or TEAACH method. There are different models of school/centered based programs. Examples of the different programs can be Public School Programs, University based programs, and private schools specifically for the treatment of children with Autism.

One example of a model used in the schools, is a program found in the Montgomery County Public School system, more commonly known as the Pre-School for Children with Autism. In the book "Right from the Start" (1998), Sandra Harris and Mary Jane Weiss highlight what they have found to be the best programs for Autism in the country. This particular program's philosophy is that, "creating specific classrooms that serve an entire school district can be both cost-efficient and maximize the likelihood of having many well-trained

individuals on staff. That is the general philosophy proposed by a federal funded model demonstration program”(pg. 49).

This program allowed for only six children per class. They each had a full time teacher, two full-time aids and three part time assistants. This essentially allowed the children to be in direct one-on-one instruction for their whole day. More specifically this “staffing allows for the children to spend most of their time in student/teacher ratios of 1:1; although teachers also provide instruction in groups (2:1 to 4:1) during parts of the day”(pg 50). Related services such as speech, occupational therapy and physical therapy are available as needed. Inclusion for the Montgomery County program occurs primarily with children in Head Start and kindergarten classrooms located in the same building. This arrangement allows the children with Autism to move flexibly between the classes based on their needs. Family involvement is considered integral to the program.

For a University based program, Harris and Weiss (1998) discussed the Douglass Developmental Disabilities Center at Rutgers University. This program had a layered component. Students initially enrolled are placed in the “Prep” class, which is a class of six children with one-to-one instruction, all day. The next class is the “Small Group” class where, again, there are six children in the class, but there are three or four staff members. The next step is the “Small Wonders” classroom, where there are six children, who have Autism and seven typically developing peers. There are, usually, four adults in the classroom and this helps the student transition down to less attention, daily. The work, here, is done mostly in groups, to help the children transition from the individualized attention, to more group setting activities, that take place in the typical classroom. Additionally, a speech-language specialist is assigned, at least half time, to each class. Parents are provided with training in behavioral techniques and are

given visits at home to help them to develop a supplemental home program, which is considered to be a very important aspect of the children's development. There are conferences during the year between the staff at the school and the parents, to ensure that communication is being maintained, and that any transitions to a different class are systematically planned out.

The Private School setting Harris and Weiss (1988) discussed is. "The Princeton Child Development Institute", which combines the components of a school based program, and a home based program. The children, who are enrolled, receive 15 hours of center-based intervention, and 20 hours of home based intervention. This aspect is different than most other programs because it combines the advantages of a school-based curriculum with the advantages of a home based program. This particular program does not have set classrooms, but, as children master different goals they are moved to different areas, so that they can generalize those skills and apply them to different situations.

A University based school that the authors looked at is located at Emory University in Atlanta, Georgia. The name of this program is The Walden Pre-School This program is different than the previous ones discussed. "A ratio of one adult to three children is typical of with a lead teacher and four or five assistants. The emphasis in the Walden program is on social integration, with children with Autism and their normally developing peers being part of the same classroom from the early days of the child's enrollment. There is strong emphasis on teaching the children how to interact with one another".(Harris & Weiss, 1988) This program relies on incidental teaching more than the structured teaching that is usually seen with programs for children with Autism. "Incidental teaching requires the teacher to make interesting settings that will attract the child's attention and then capitalizes on the child's interests to convey the information. For

example, if a child picks up a truck, the teacher might comment on its color or shape and ask the child a simple question” (IBID, pg. 51).

There are other therapeutic interventions that cannot be ignored in the treatment of Autism. These different interventions will be discussed in the Literature Review.

RESEARCH QUESTIONS

Through the use of various Internet mailing lists or “List Serv’s” and a survey of the participants of the lists, I looked for the following:

1. What are the most popular methods of intervention?
2. What does research show us about Autism and intervention?
3. How satisfied are the parents with their method of choice?
4. The amounts of time families spend each month researching current methods of intervention for their children.

Chapter Two –Literature Review

Considering that few insurance companies have paid the cost of these programs, there have been many articles which have shown that these types of treatment are not only cost effective but successful for the child, as well. The popularity of these programs began when Catherine Maurice, a parent of 2 children with Autism wrote the book, “Let Me Hear Your Voice: A Family’s Triumph over Autism”. In this book, she detailed what steps she took to help both her children overcome their symptoms of Autism. She used a combination of approaches. They included, mostly, applied behavioral analysis, but, included holding therapy, as well as other methods to help her children.

Her book was well received by many parents, as it was the one of the first books written, in journal form, that showed the success of two children, who were able to overcome the symptoms of Autism. In her second book, “Behavioral Intervention for Young Children with Autism: A Manual for Parents and Professionals”, various interventions and methods are discussed for parents to use in a home program. This book was put together by Ms. Maurice and many others, who have recently, contributed to the field of Autism research. Each chapter was written by a different researcher or therapist, and discusses the essential elements that contribute to the implementation of a home program for an Autistic child.

In chapter three, “Early Behavioral Intervention for Autism: What Does Research Tell Us”, Gina Green discusses Applied Behavioral Analysis. This method can result in dramatic improvements for children with Autism, as well as, successful integration into regular schools, and normal functioning for some. She goes on to say that there is scientific evidence that, “Applied Behavior Analysis methods (also called behavioral intervention or behavioral treatment) can produce comprehensive and lasting improvements in many important skill areas for most people with Autism, regardless of age.” Some of the research that has been published which outlines the effectiveness of this treatment approach is The UCLA Young Autism Project,

The May Institute Study, The Murdoch Early Intervention Program, The UC-San Francisco Study, and, as stated earlier, the Maurice Children.

The first published study that showed effectiveness of this type of treatment program was the UCLA Young Autism Project. This study was published in 1987 in the "Journal of Infants and Young Children", and was titled "Intensive and Early Behavioral Intervention with Autism: The UCLA Young Autism Project". In this project, Dr. Loovas studied approximately 60 children who received different levels of intervention. The experimental group received 40 hours of intervention per week. Control Group One received approximately 10 hours per week of intervention and Control Group Two received no intervention from the Young Autism Project. What Dr. Loovas found was that the one-to-one teaching that took place across all environments, produced the most improvement over both the long and short term, for those children. All of the children were evaluated at a later date and 47% of those who were in the experimental group had completed "regular" first grade, and those, then, participated in another follow-up study. These successful children were, again, evaluated when they were 13. Those who evaluated them were not familiar with their histories, and found that the majority of those children had maintained those gains, and were still succeeding in school.

The May Institute Study showed success using this type of intervention, as well. Their study was similar with the exception that they used children who were slightly older. and who were slightly lower in functioning. Their success was around the 47% mark, as was from UCLA. They received their intervention from programs that had no contact with the other project. One difference, that is important to note, even though they improved, they were not put in typical classrooms like the children in the UCLA Young Autism Project. Another difference was the amount of hours per week spent on intervention. In the May study, they used

approximately 20 hours per week, and the UCLA project used 40 hours per week.

It should be noted that the May Center for Early Childhood Education provides a full range of services for children with Autism. In the article titled, "The May Center for Early Childhood Education: Description of Continuum of Services Model for Children With Autism," (Campbell, et.al., 1998) information is provided regarding their services.

They begin their article with the historical implications of PL 99-457 and its impact on services to children with Autism. According to the authors, the center was founded in 1983 with a federal grant to evaluate outcomes from intensive applied behavior analysis intervention for young children with Autism. In 1986, an integrated preschool was started as a response to the fact this population was being undeserved. The article goes on to discuss how applied behavior analysis is an effective approach, as was found in the study. They state, "Over 30 years of controlled research has demonstrated that applied behavior analysis is a highly effective method of intervention, if not the treatment of choice, in providing education services to children with Autism".(pg. 174)

The authors go on to describe all the programs that the May Center offers. Beginning with the Home-Based program, there are three service delivery options that a parent can use, based on the child's age, and the focus of intervention. With the early intervention program the services begin with 4 – 20 hours weekly in the home. The services that are provided are speech therapy, occupational therapy and, physical therapy. In addition, social workers and a developmental educator come to the home to work with the children, and provide parents with the skills, that they need, to help their children succeed. Parents are encouraged to be their children's therapists at least 80%, of the time and as the children get older, the services change. However, they can still be provided in the home. Data is collected by those working with the children to ensure that the children are making progress and obtaining the necessary goals to further their education.

It should be noted, that the May Center is a replication site of the UCLA study by Dr. Loovas. Currently, there are replication sites all throughout the country, that are administering

therapeutic interventions, in the same way that Dr. Loovas did, in order to see if his high rate of success can be replicated with others. This is being done to, “replicate the diagnostic assessment, and treatment procedures developed at the UCLA Clinic for Behavioral Treatment of Children, (b) produce significant improvements in intellectual, academic, communication, self-care, and socioemotional functioning, and (c) identify parameters which predict the most robust outcomes”.

The other options that the May Center offers is a Day-School program. This program offers pre-school and kindergarten classrooms which are both integrated and non-integrated. In the state of Massachusetts most pre-school and Kindergarten classes are only half days, whereas the May school offers these children full day services, which can be advantageous for children with Autism. Finally, it should be noted that there are consultation services available for families who do not live close to the center, but are still in need of services. One of the most critical aspects of the May program, that must be noted, is the focus of the program, which is to have the children progress out of their program, and back into their local school. Not only is the focus to get them back to the local school, but according to the article, “ Staff work directly with public schools to ensure that children’s transitions are properly supported and essential teaching procedures are implemented”. This aspect is so critically important to students with Autism.

Another study was done with the UC-San Francisco. This was done as a follow up to children who had received their initial diagnosis at the Pervasive Developmental Disorder Clinic, Langley Porter Psychiatric Institute, University of California at San Francisco. These researchers noticed that a, “number of children were reported to have received intensive, home-based behavioral intervention” (Green, 1996, pg. 35). They, then, paired these children, who had not received behavioral intervention, but, whose chronological age, mental age, diagnosis, and intervals between evaluations, were similar. Other variables were considered such as trainers, amount of time spent in intervention, who the trainers were, and the amount of time these children, additionally, spent in school. What they found was those, who participated in home programs, had IQ’s which had improved, in substantial amounts. Those who did not receive the

behavioral treatment, in certain cases, saw a decrease in IQ scores.

The information in all of these studies show that behavioral intervention can be an effective way to help a child overcome their symptoms of Autism. What has been shown in these recent studies is that the setting is not as important as the method, quality and quantity of the intervention for the child.

Another article that discusses interventions for children with Autism is called, "Early Intervention with Children with Autism: The Search for Best Practices" was found in the Journal of the Association for Persons with Severe Handicaps. This article was published in the fall of 1999. According to the author, Richard Simpson,

"Autism is truly the quintessential enigma of disabilities. That the onset of Autism and pervasive developmental disorder occurs early in life and the prognosis for persons with the disorder is generally considered to be poor makes early diagnosis and intervention, including educational intervention, essential. As consistently noted by the authors of this special issue, little disagreement exists that early and effective intervention bodes well for improved outcomes across the life span for children diagnosed with Autism-related disorders. As revealed by far too many case histories, lack appropriate early intervention can be associated with serious negative outcomes."

"Despite and almost universal agreement regarding the need for early intervention, considerable and often strident debate exists regarding what the intervention or treatment should be. To complicate this matter, an ever-growing proliferation of treatments and interventions exist for ASD, at least some of which are associated with claims of a cure."

As noted earlier, this leads to many parents having great difficulty when trying to determine which intervention will be best for their children. Mr. Simpson does go on to review what has been discussed in recent publications, and does try to provide an overview of what has been shown to be somewhat effective.

He discusses the article, "Pivotal Response Intervention 1: Overview of Approach", which will be discussed later in this paper, and reminds readers that according to the authors of that

article it is critically important to address “targets that are central to many areas and that thus have the greatest probability of having widespread positive effects on many behaviors”.

Mr. Simpson also presents information on how valuable incidental teaching can be. Mr. Simpson discusses what McGee, Morrier and Daly wrote, in 1999, about the Walden Childhood Program at Emory University. “Incidental teaching to instruct young children diagnosed with Autism-related disorders. Although much of their emphasis is on the development of social skills, McGee and her associates leave no questions that incidental teaching has widespread application to a number of other domains”. Mr. Simpson, also, goes on to state, “Although incidental teaching methods offers numerous applications, not the least of which is enhanced skill generalization, ease of application is not one of them”. Skill generalization is often problematic for children with Autism. They often do not know how to transfer skills that they have learned in one environment to another.

This article also discusses the controversy associated with the use of Applied Behavior Analysis. Mr. Simpson states:

“ Individuals who are involved with programs for children with Autism are increasingly encountering parents and some professionals who are requesting total and exclusive use of discrete trial methods, typically within a one-to one context, for 40 or more hours per week. Discrete trial methodology is a useful tool. However, to advocate for exclusive use of this method implies that other tools and strategies are not more effective in given circumstances”.

He goes on to say that:

Moreover, in the absences of reliable data regarding the extensive use of any intervention strategy, including discrete trial training, it appears prudent to individualize strategies to fit the children for whom they are designed. Although the use of any program in whatever setting may be appropriate and efficacious for some children, families and professionals, no one program is likely to be suitable to all children.”

Finally, in this section of his article he informs us that school administrators and educational licensing boards are being besieged with requests for these programs. He states, that while

discreet trial can be done by a great many people, he questions why every child, that is diagnosed with Autism, has to be treated with a discreet trial program.

Finally, Mr. Simpson quotes Heflin and Simpson's work of 1998 that suggest parents, teachers, and therapists should ask themselves the following five key questions when determine the therapeutic interventions for children with Autism. They are:

1. What are the anticipated outcomes of a particular option, are they appropriate and meaningful and do they match a student's needs including his or her individualized educational goals and objectives?
2. What are the potential risks associated with the use of various in interventions, including health or behavioral risks for the student; quality of life for the child, his or her family, and the school personnel involved in the intervention; and the implications for the child and family if the treatment fails?
3. How will the option be evaluated, including how progress will be demonstrated and measured; who will be doing the evaluations; how often the effectiveness of the interventions will be evaluated; and what criteria will be used to determine if a treatment should be continued or changed?
4. What proof is available that the options is effective, such as quantity, quality, and variety of sources attesting to the effectiveness of an option; whether information regarding an intervention is published in peer-reviewed journals; and whether the validation is primarily of an empirical type or drawn from personal testimonials?
5. What other options would be excluded if a particular option is chosen?

These are valuable questions, that parents and educators should ask themselves when trying to determine what interventions would work best for the children.

There have been other therapeutic interventions for Autism that have received national attention recently. One is known as Secretin. The national exposure ranged from articles in the New England Journal of Medicine to stories on Good Morning America and Dateline. The stories publicized examples of families using the drug to reduce their children's symptoms of Autism. Dateline NBC carried a story about Victoria Beck and her son Parker and his rapid improvement after Secretin was administered. In April of 1996, Mrs. Beck took her son to the University of Maryland for testing because her son, in addition to his symptoms of Autism, was experiencing severe gastric problems. According to the article, in the Wall Street Journal on

March 10, 1999, many children with Autism experience these difficulties. The doctor administered an endoscopy and also gave him a dose of Secretin, which stimulates the pancreas to produce gastric juices. These tests did not reveal the cause of Parkers digestive problems, but within a week the Becks noticed differences in Parker. Not only was the child sleeping better but also his digestive problems had improved. For approximately three months after Parker kept improving and then it seemed to stop. Mrs. Beck became panicked and began researching what it was that could have helped him. She concluded that it had to been due to the Secretin that was administered during the testing. She contacted the University of Maryland and they were skeptical about Mrs. Beck's theory. After a period of time, difficulty and determination on Mrs. Beck's part she was able to obtain additional infusions of Secretin for her son, and, also, obtained the patent for the treatment of Autism using Secretin. Mrs. Beck, in turn, has assigned the patent to a small firm called Repligen. The reasons she joined forces with this firm is that the owners are the parents of an Autistic child who benefited from an infusion of Secretin.

Secretin is a polypeptide hormone. It is also a neurotransmitter, a chemical messenger, in the neuropeptide group. It is one of the many hormones that control digestion. It is a polypeptide composed of 27 amino acids and is secreted by cells in the digestive system when the stomach empties. Secretin stimulates the pancreas that emit digestive fluids that are rich in bicarbonate which neutralizes the acidity of the intestines, and the helps the stomach to produce pepsin and the liver to produce bile

(<http://www.curr.edschool.virginia.edu/go/cise/ose/information/Secretin.html>). Secretin's primary use is to increase the amount of bicarbonate and the ph of pancreatic juices. It also helps the pancreatic enymes work better.

The exact way it works to change the symptoms of children with Autism are not known, at this time. However, the following changes have been documented when it has been used:

- Changes in blood serotonin levels (neurotransmitter).
- Enhances intestinal fluid antibody levels to cow's milk and other proteins
- Drop in rubella titer and/or mumps levels from high to normal.
- Improved blood flow to the brain in some children on SPECT scan
- Drop in blood ammonia levels.
- Normalization in bowel movements
- One known report of clearer vision.
- Reports of intestinal fungal and bacterial levels dropping

(<http://www.nationalspeech.com/news/index.html>).

According to Bernard Rimland, Director of the Autism Research Institute "Secretin continues to look like a very promising-perhaps the most promising-treatment for Autism"(<http://www.Autism.com/ari/Secretin2.html>). Dr. Rimland goes on in his article to discuss different aspects of the pros and cons of the usage of Secretin. He discusses the problem with the short supply, and the fact that the use of Secretin, in the treatment of Autism is still considered "off-label". When you use a medicine for a purpose other than what it is normally used for, it is considered "off-label". Many doctors will be hesitant to use Secretin for the purposes of treating Autism. Dr. Rimland poses various questions in this article: Who is the best candidate for treatment with Secretin? From the data collected from various families to date, they are unable to determine who would be the best candidate. Many families are using the drug for their children. They have ranged from mild to severe symptomatic children, from young to old. He states that so far none of the usual predictors have been true. They have found that those children who suffered from diarrhea have responded better behaviorally but negligibly so.

What would be the best dosage was also discussed. Again there are no clear-cut criteria for the dosage, but Dr. Rimland believes that it will be found that the optimal dosage will be 2.0 and 3.5 CU/kg.

Most importantly he discusses the benefits and adverse effects. The most commonly reported improvements is an increase in eye contact, awareness, sociability, speech, and better sleep habits. The adverse effects, from the data he has collected to date, have been mostly cases of hyperactivity and aggressiveness. Dr. Rimland does point out that at this point we should not assume that the Secretin causes these effects as children with Autism have these tendencies to begin with, and that further research is needed. Dr. Rimland reports these results from completed surveys from parents whose children have been administered Secretin and have faxed in those responses (See appendix A).

Another doctor who has had experience with the administration of Secretin is Sidney Baker, M.D.. Dr. Baker is a practicing medical doctor with over thirty years of medical experience. He is currently a private solo practitioner, who has been administering Secretin to children who have Autism.

In his Internet site found at <http://www.sbakermd.com./info/Autism/Secretin.htm> he discusses many of the aspects of Secretin. He tries to explain the pros and cons of Secretin so that all can understand. He defines Secretin as, “ a hormone normally present in the body that serves as a message carrier from the upper small intestine, just past the stomach, to the pancreas and liver. The message is ‘food has arrived, please squirt digestive juices onto it!’. When the message is received the pancreas and liver deliver their digestive juices to greet food as it passes from the stomach into the upper part of the small intestine”. He believes that the cost of the materials to treat a child with Secretin could run approximately \$230 - \$300 per infusion. Dr. Baker states that he has treated approximately 150 children, already, and only a few have had adverse reactions to the Secretin. He also discusses many of the side effects that he has witnessed. These range from children who have gotten red lips immediately after the injection,

some vomiting, some whose behavior temporarily got worse, and temporary loose bowel movements. The discussion on his web site then moves to the benefits that he has seen with children who have received Secretin. He has seen children who had previously been unable to be potty-trained attain that goal in as quickly as three days. He, also, states that most children had improved bowel function, reduction in food intolerance, eye contact, speech, general awareness and calmness.

Dr. Baker administers Secretin using, “a butterfly intravenous needle into the vein in the arm as for drawing blood. The injection usually requires less than a minute but it can be done more slowly if the situation permits a leisurely pace”. According to his records benefits can be seen “within days to weeks – usually in the first week. If no benefit is seen after 6 weeks, there is still room for delayed improvement”.

Dr. Baker updated his website in late September, 1999. He still has found an over 70% positive response rate to Secretin. He states that,

“The the main impression I have gained is that this is by far, the best thing that has come along for children with problems in the Autistic Spectrum. Responses such as Parker Beck are rare, but most of the stories, I hear, from parents are full of poignant examples of progress in language and focus, as well as in bowel function, in kids who have had problems in this area. So far, we can find no statistical correlation’s that allow me to make any selection of good vs. bad candidates for Secretin. Age, gender, presence of bowel complaints, behavior profiles, lab data of all kinds have been looked at by Lee Fleming and Stanely Thompson. So far, we see no useful patterns emerging from the data. The inconsistency of response, in some children, from infusion to infusion is remarkable. The delay of improvement, in some children, contrasts dramatically with the nearly immediate response seen in others. I have a few children who appeared to have no benefit in the month or two following infusion but went on during the ensuing year to make leaps in development that had never been seen before and were not associated with any new intervention”(http://www.sbakermd.com/info/Autism/Secretin.htm).

As positive as Dr. Rimland and Dr. Baker are about the use of Secretin in the treatment of children with Autism, others are not as positive and there have been studies that have shown, on a limited basis, that Secretin has no effective on the symptoms of Autism. One study that has been conducted titled “A Double-Blind, Placebo-Controlled Trail of Secretin for the Treatment of Autistic Disorder” (http://www.members.tripod.com/trainland.Secretin.html) found

very little, if at all, differences in children who had been treated with Secretin as compared to those who had not been treated. The objective of the study was to study the efficacy of intravenous porcine Secretin for the treatment of Autism. The method that they used was a “randomized, double-blind, placebo-controlled crossover design, 20 subjects with Autistic disorder received either a Secretin or placebo infusion at baseline and the other substance at week four. Subjects were given the Autism Diagnostic Interview-Revised, the Autism Diagnostic Observation Schedule-Generic (ADOS-G), and other pertinent developmental measures at baseline and at weeks 4 and 8 to assess drug affects.” The results were “for the primary efficacy analysis, change of ADOS-G social-communication total score for week 0 to week 4, no statistically significant difference was obtained between placebo (-1.0 ± 2.4) and Secretin groups (-0.7 ± 1.4 ; $t\ 0.34$, $df\ 18$, $P < .74$). No significant differences were obtained for the other measures, including when all 20 subjects were compared by paired t-test from baseline to 4 weeks after Secretin infusion.” The conclusion that the researchers came to was “there was no evidence for efficacy of Secretin in this preliminary randomized controlled trial”.

The data from this study was collected at various centers including the University of California-Irvine and the University of Utah.

Contrary to Dr. Rimland’s discussion and results from his SOS survey, this study stated that Secretin showed no improvement in children with Autism. Even though the study is contrary to previously discussed positive aspects of Secretin the authors do point out the limitations of this study. The first is the small size of the study. Originally there were only 21 children who were participating in this study. One was excluded because certain characteristics were not found in this child so they excluded him/her from the study. Also, due to the reporting methods used, a positive response could have been missed. The children participating in this study were only given one dosage of Secretin and were assessed at 4 weeks and then again at 8 weeks. A positive response could have been missed at the 2-week interval. In addition, the dosage amounts may have been insufficient to show any change on this particular population of children. The authors of the study do point out that this study is a part of a planned larger study that will include over 60 children.

“ The information age has accelerated the rate at which communication occurs in a way that may not always be advantageous. There is a considerable lag time between the time when word spreads about a new treatment in Autism and the time when controlled testing can be done. During this time period, it is difficult for parents of these children to make decisions. The recent publicity of Secretin as a potential treatment for Autism has put both clinicians and parents in these unfortunate situations. Faced with a patient or child with this debilitating disorder, many parents feel compelled to try the latest treatment. In the case of Secretin, many would argue that it is worthwhile to try Secretin as it may prove helpful and has been shown through the years of testing by gastroenterologists to be relatively safe”. (Owley, 1999)

This statement along with Dr. Rimland’s publication show how many parents do feel compelled to try anything with minimal risk to help their children with Autism.

Another aspect used in the treatment of Autism is through the use of diet modification.

One approach that is used is a Gluten and Casein Free Diet. In order to understand the reasoning behind the removal of these substances in children with Autism, a short discussion regarding their origins should be explained.

In the article “An Experimental Intervention for Autism, Understanding and Implementing a Gluten & Casein Free Diet, Lisa Lewis, Ph.D. explains the following:

“Glutens are proteins found in the Plant Kingdom Subclass of Monocotyledonae (monocots). These plants are members of the grass family of wheat, oats, barley, rye and triticale, and their derivatives. Derivatives include: malt, grain vinegars, soy sauce, grain alcohol, flavorings and the binders and fillers found in vitamins and medications. Casein is a phosphoprotein of milk, which has a molecular structure that is extremely similar to that of gluten.”

With that basis in mind Dr. Lewis then quotes the following passage of an article written by the Autism Research Unit of the University of Sunderland (Great Britain).

“In the early 1980’s a number of researchers, including Herman and Pankespp, noted the similarities between the behavioral effects of animals on opioids, such as morphine, and the symptoms of Autism. In a very speculative paper, Pankese proposed a mechanism whereby people with Autism may have elevated levels of opioids, which occur naturally in the CNS (brain) of humans. The best known of these naturally occurring opioid

compounds is beta-endorphin (endogenous morphine) and certainly there is a degree of correlation between the known effects of this compound and the symptoms of Autism.

Just after this, Gillberg produced evidence of elevated levels of "endorphin like substances" in the cerebro-spinal fluid of some people with Autism. In particular, elevated levels appeared in those children who appeared to feel pain less than the normal population and who exhibited self-injurious behavior. At about the same time, Reichelt produced evidence of abnormal peptides in the urine of people with Autism. We ourselves, like a number of other groups, attempted to replicate his findings. Although his technique was comparatively simple there were technical difficulties and these attempts were, initially unsuccessful. Later on we switched to a more sophisticated technique and have been able to confirm Reichelt's findings. **In the urine of about 50% of people with Autism there appear to be elevated levels of substances with properties similar to those expected from opioid peptides.**

The quantities of these compounds, as found in the urine, are much too large to be of CNS origin. The quantities are such that they can only have been derived from the incomplete breakdown of certain foods. Proteins consist of long chains of units known as amino acids. Normal proteins are digested by enzymes in the intestines and are broken down into these units. However, if for some reason, this digestion is incomplete, short chains of these amino acids (known as peptides) will result. It is proposed that these peptides may be biologically active and could result in the symptoms, which we see in Autism. The majority of these peptides will be dumped in the urine, which is where Reichelt and we are finding them. A small proportion will cross into the brain and interfere with transmission in such a way that normal activity is altered or disrupted. It may be that these compounds, themselves, have a direct effect upon transmission or that they will attach themselves to the enzymes which would break down our own naturally occurring enzymes. The consequences would be the same in either case.

It is well known that casein (from human or cow milk) will break down in the stomach to produce a peptide known as casomorphine, which, as the name implies, will have opioid activities. Similar effects are noted with gluten from wheat and some other cereals [notably oats, barley and rye] in which the compounds formed are gluteomorphins [or gliadinomorphins.]

If this opioid excess hypothesis is correct, there are a number of strategies which can be adopted. Firstly the anti-opioid drug "naltrexone" could be considered and promising results have been reported. Alternatively a diet which excludes casein (milk and dairy products) or gluten (wheat and other grain products) could be considered. It may be possible to determine from the pattern of the urinary peptides, whether casein or wheat or both should be avoided, but such conclusions may be premature at this stage. It has been observed that those children whose Autism appears at or around the time of birth may have a problem with casein whereas those whose Autism becomes apparent at about two years of age, when a wheat based diet is more likely to be adopted, have particular difficulties with gluten. Some children may have difficulty with both.

The practical aspects are then discussed:

The theoretical processes described here are toxicological in nature rather than allergic. The results are akin to poisoning rather than an extreme sensitivity such as occurs in coeliac disease or sensitivity to certain food colourings. Removal of gluten and/or casein containing products requires the active participation of all those concerned with the child's well-being. Tests have often been ruined by a well meaning relative who ignores parental instruction, or by schools or therapists who feel that the proposals are rubbish. Carers must satisfy themselves that the diet is being adhered to before any evaluation is possible. Gluten and Casein free products, together with advice on their use, are available from Pharmacies [in this country health food stores will be the best source.] Nutritionists and dietitians would also be able to advise.

Initially the reported effects may be negative, upset stomach, anxiety, and clinginess and slight ill temper. Experience would suggest that these are good signs and precursors of a positive response. Reichelt recommends a trial period of three months. If it has not worked within that time it is unlikely to do so. Experience also suggests that the results are more easily demonstrated in younger children. The effects in fully-grown individuals appear less impressive. Given that there appear to be a number of possible causes of Autism it is not unexpected that no unitary solution will be found for all cases.

Finally, the conclusions drawn are:

Although the hypotheses may appear "off the wall" in many respects, there are a number of pieces of evidence, which support them. The ideas are compatible with virtually all the accepted biological data on Autism and are worthy of consideration.

The dietary method must still be considered as experimental and no positive results can be promised or are claimed. The use of diet may well be far less harmful than other medical interventions or therapeutic regimes.

Dr. Lewis goes on further, in her article, to discuss the implications of others that have used this intervention with positive results. The conclusion of her article uses examples of children who have used this intervention with success. Thus, the removal of casein and gluten would reduce the peptides released in these children and, thereby, reducing the symptoms of children with Autism. It is also concluded that there could be no harm in trying this diet for periods of time, as it is not a drug, and cannot be considered harmful.

According to the website www.gfcfdiet.com there are various foods that should be eliminated from a child's diet once they are started on the Gluten and Casein free diets. Examples of some foods that should be eliminated are:

White Vinegar (may not be gluten free)	Milk	High Gluten Flour	Wheat
Soy Sauce	Yogurt	Caramel Coloring	Couscous
Bread	Pasta	Cookies	Doughnuts

Examples of foods that can be included in a Gluten and Casein Free Diet are as follows:

Tuna Fish packed in Spring Water	Fresh Meat	Boars Head Lunch Meat
Ore-Ida Potatoes	Health Valley Soups	Fresh Vegetables
Dole Pre-Cut Salads	Rice	Soy Original GFCF

While these are small examples of what can and cannot be included, advocates for the Gluten and Casein Free diets stress the importance of complete elimination of these foods from the children's diet. It is very important to the success of this intervention that thorough research is done to ensure that all foods are eliminated. Parents are urged to read the labels of all products that they buy before serving it to their children. Many times it would appear to be an acceptable product but, upon closer review, casein or gluten is included in the ingredients.

Another therapy that is used by parents is the administration of Vitamin B6 and magnesium. In the article titled Vitamin B6 (and magnesium) in the treatment of Autism, by Dr. Rimland of the Autism Research Institute, he, strongly, advocates the use of Vitamin B6 and magnesium for all children with Autism.

The article focuses on the history and studies of B6 in the use of treating children with Autism. According to Dr. Rimland, research began with this therapy and Autistic children in the late 1960's. "In 1966 two British Neurologists, A.F. Heeley and G.E. Roberts, reported that 11 of 19 Autistic children excreted abnormal metabolites in their urine when given a tryptophan load test. Giving these children a single 30mg table of vitamin B6 normalized their urine;

however, no behavioral studies were done.” This, in turn, made Dr. Rimland think more about the relationship between Autism and vitamin therapy. He began receiving inquiries from parents after the publication of his book, *Infantile Autism*. As a result of these inquiries and Dr. Rimland’s own personal interest (he has a son who has Autism, who is currently in his early 40’s) he surveyed approximately 200 Autistic children, who were taking megadoses quantities of vitamins. From this trial, he found that only Vitamin B6 was the most important of the different vitamins that the children were taking. He, later, undertook a second study which confirmed many of his findings from the first. The improvements ranged from better eye contact, less self-stimulatory behaviors, more interest in the world around them, less tantrums, better speech and improved interactions with others. These children, according to Dr. Rimland, were not cured but were much better than they had been, previous to taking the vitamin therapy (<http://www.austim.com/ari/editorials/vitb6.html>). As with every treatment in which you are altering your metabolic system, the question of safety must be brought up. According to Dr. Rimland, there are no significant side effects from the administration of vitamin B6 in the treatment of Autism. This again, is a therapy that has not been proven to “cure” Autism but it has been shown in certain instances to reduce the severity of the symptoms. Dr. Rimland, did report in certain instances, there were adverse effects in children, such as numbness in the feet and hands, but in each of those limited cases, once the amount administered was reduced, the adverse effect was eliminated.

Another group of therapies that have been used on children with Autism are referred to as Sensory Motor Therapies. These therapies include Sensory Integration Therapy, Auditory Integration Training and Facilitated Communication. Historically, it has been believed that children with Autism have difficulty processing sensory stimuli from the environment and

translating that input into effective action. According to Tristram Smith in his article, "Are Other Treatments Effective" (1996) he states "Consequently, according to theorists, such children have difficulty perceiving and responding to environmental events. Moreover, they try to moderate their arousal levels by engaging in ritualistic behaviors such as rocking their bodies back and forth". He goes on to assert that "At one time or another, many of the most influential figures in the history of special education have advocated such therapies: Itard, Seguin, Montessori, Frostig, Delcato and others. These educators believed that by getting to the root of children's learning difficulties, the therapies could cure developmental disabilities. Even though this theory may or may not be true, these therapies, today, are used in the treatment of Autism.

One of these types of therapies used to treat children with Autism is called Sensory Integration Therapy. This type of therapy is usually administered by licensed occupational therapists, in either the public schools, or in the therapist's private office. In Sensory Integration Therapy, the therapists, "stimulate children's skin and vestibule system. This stimulation consist of activities such as swinging in a hammock suspended from the ceiling, spinning in circles on specially constructed chairs, brushing children's bodies, and engaging in physical activities that require balance"(Smith, pg. 49).

Another definition of Sensory Integration describes it as the,

"process on the brain which organizes sensory experiences – touch, movement, body awareness, sight, sound, and the pull of gravity – into unified information which the individual uses in learning about reacting to the world around him or her. Sensory integration dysfunction is the inability to construct useful information from sensory experiences (<http://www.southpawenterprises.com/sensory.htm>).

Additionally, this article states,

"The sensory integration approach is rich in vestibular, proprioceptive, and tactile inputs; areas where many children with neurological issues have deficit's. The approach seeks to engage the nervous system to process and integrate sensory input in organized and meaningful ways, which will ultimately enhance the ability of the nervous system to

function more adequately. Each adaptive response, as it provides feedback into the nervous system, encourage maturation and organization of the nervous system at increasingly higher levels. Ultimately the individual is able to interact with his/her environment in more successful and adaptive manners”.

Another article entitled, “The Efficacy of Sensory Integration Procedures” written by Sharon A. Cermak, Ed.D., OTR and Anne Henderson, Ph.D., OTR (1990) reviews how to implement this type of therapy, and what outcomes should be reviewed. They state that in order to effectively administer this type of therapy the following are characteristics of what should be done in sensory integration therapy. These characteristics are:

- Active participation
- Child directed
- Individualized treatment
- Purposeful activity
- Need for adaptive response
- Input varies based on child’s response
- Activity rich in proprioceptive, vestibular and tactile input
- Implied or stated goal of improving processing and organization of sensation (not the teaching of specific skills)
- Administered by a trained therapist (either a occupational therapist or a physical therapist)

They do go on to discuss the effectiveness of Sensory Integration Therapy. While they state that there has been studies, there has not been a consistent agreement regarding the effectiveness of this type of therapy. They go on to state, that many parents whose children have been treated with this type of therapy feel that it is very effective.

Also, included in this article, was a summary of a meta-analysis performed in 1982 by Ottenbacher. His, “meta-analysis of SI effectiveness studies yielded an overall effect size of $d=0.70$ which is considered to be a medium effect size. According to Cohen, a d -index of this magnitude means that the average performance of subjects experimental groups receiving sensory integration procedures was better than 78.8% of the subjects in the control groups not

receiving the therapy”. While these numbers are not highly supportive, it should be noted that there were only eight studies that were included in this meta-analysis, due to inclusion limitation.

The authors then go on to discuss why they believe that this type of therapy does work. They state that “ we are influencing brain organization and brain change. The idea that the neural organization is actually changing or developing as a result of the sensory input/adaptive response is controversial.” They state that even though this is controversial and difficult to support, one can determine if this therapy is effective by observing whether or not children’s behaviors are appropriate after supplying a specific input. Finally, they state that much of their intervention research has come from the pre-test, post-test model. They have observed many children who have changed, over time, from this type of intervention. They have received comments from different family members and teachers working with their children who have stated “Johnny seems so much better organized better now”. Using these type of comments they determine that Sensory Integration, if properly administered, can be of benefit to children with developmental delays, and children with Autism.

Chapter Three – Research Design

As stated earlier, the goal of this project is to determine what treatment options are currently being documented by researchers. The second part of this project is to determine what parent's are actually using, their satisfaction with the intervention chosen, and how they correlate to what the researchers are stating.

In order to reach as many parents as possible I chose to use the Internet. On the Internet, there are "List Servs" that address different issues. These list servs are essentially group e-mail discussions. A person can join the list by sending a simple message to the computer system that hosts the list serv. A University or private group can offer their computer system to host these list servs. Once the message has been sent, and been processed, the new participant receives many e-mails regarding that subject. There is, usually, a list owner who often acts as a moderator. In certain instances, there are private list servs. In those cases, you must send a message directly to the list owner explaining why you want to participate. If that meets the approval of the owner, you will be added to the list. In appendix B are copies of the rules that govern the lists that I sent my request to.

It should be noted that out of professional courtesy I contacted the list owners of these list servs prior to sending any information to the list. I also decided, in advance, that I would request all participants to contact me directly rather than posting the questions directly to each list. This type of request from the list servs is considered "off-topic." Off-topic is referred to on the Internet when the discussion does not apply to all those involved. It is also considered rude to have "off-topic" discussions on the list.

That being said, the first one that I received permission from was the "me-list". This list focuses on the use of applied behavioral analysis. This is a parent-focused list and is considered

a “private” list. In order to join this particular list serv you must send a message directly to the list owner explaining who you are and why you would like to join. If this meets with her approval, she will directly add you to the list. Since this list is dedicated to parents and teachers, administrators are often not allowed to join the list. I would like to note, that I have been a member of this list for almost three years. The debate is lively and the information that is shared among parents is very valuable for all those reading the list. Appendix C contains the request that I sent to Ms. Allen, list owner of the “me-list”, and her response.

The second list that I received permission from is the “Autism discussion” that is hosted at St. John’s University. The list owner is a Mr. Ray Koop, who I contacted directly to obtain permission. In Appendix E is a copy of the correspondence that I had with Mr. Kopp. He, also, suggested that I join the list so that I would be sure to receive all the responses to my request. A copy of the message that I sent to the Autism list is also included in Appendix F.

Once I received permission from both, I posted similar requests to both lists. As soon as I received a request from a parent to participate, a short e-mail was written to each parent. The e-mail would thank them for participating and included the questions that I was requesting they answer. In each e-mail, parents were encouraged to write as much or as little as they chose. They were, also, advised that if they did not feel comfortable answering a question, that they should leave it blank. All parents were, also, given the option to return it by either e-mail or fax. Appendix G has a sample of the survey that was sent to parents.

Many of the surveys were returned almost immediately. The range of responses also varied. Some parents provided pages of answers and provided pictures, and others wrote very little. It should be noted that in some cases responses were received in less than a ½ hour. Once a

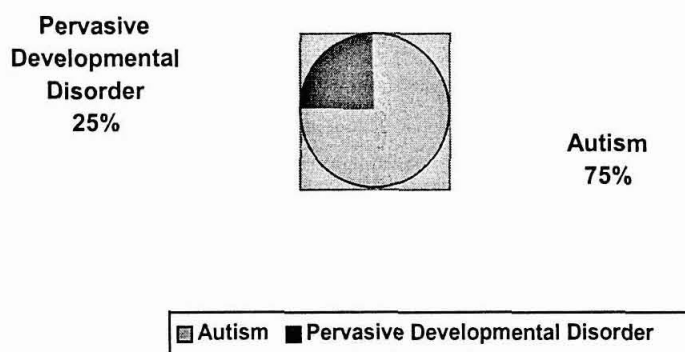
response was received it was printed and grouped according to age. They were divided as follows:

- Group 1 Birth to 5
- Group 2 Age 6 to 8
- Group 3 Age 9 and over

Finally, the survey period lasted ten days, starting at the time the post was made on the Internet to receiving responses. It should be noted that at the end of the ten-day period there were no additional request or responses.

Chapter Four – Discussion of Results

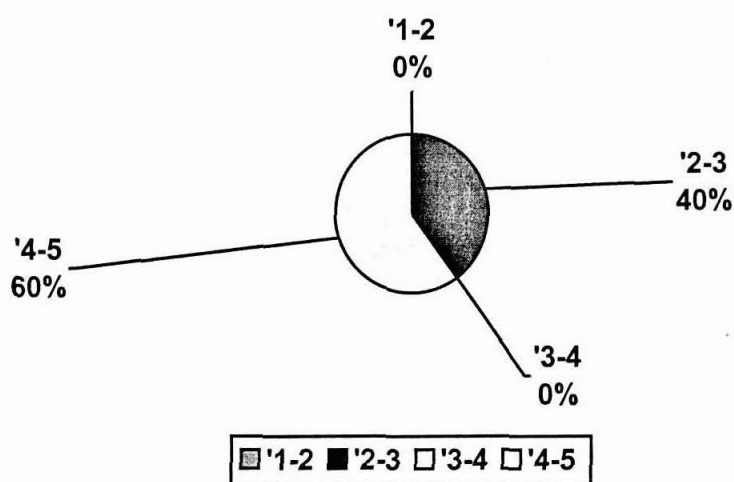
According to the list-owners the request to participate was sent to over 2,500 people. The amount of parents that agreed to participate was a small fraction. I received 126 responses from parents. For the purposes of this paper the children were divided into various categories, based on current age. The age groups that were looked at were age five and under, age six through eight and then finally age nine and over. Presented below are various graphical representations. The first group shown is an overall chart of the different diagnoses parents listed for their children.



The actual count showed that 94 children had received the diagnosis of Autism, either mild, moderate or severe, and the remaining 32 had received Pervasive Developmental Disorder. Some of the parents did indicate that they were given the diagnosis of Pervasive Developmental disorder and they did not agree with it. For counting purposes, I counted them as a Pervasive Developmental Disorder child since that is the diagnosis of record. It can be assumed from the responses received, the majority of children had received the diagnosis of Autism. However, many of the parents whose children were diagnosed with Autism are from the older age category.

The next section that was reviewed was the age of diagnosis. Surprisingly, the majority of respondent's received the diagnosis past the age of three. Seventy-six parents wrote that they

had not received a final diagnosis until after the age of three. According to the book, Characteristics of Emotional and Behavioral Disorders of Children and Youths (1997), “the three major diagnostic criteria for Autistic disorder given by DSM-IV include, in addition to onset prior to 4 years: 1. Qualitative impairment in social interaction, 2. Qualitative impairments in communication and 3. Restricted repetitive and stereotyped patterns of behavior, interests and activities. Using this information, I was quite surprised at the amount of respondents who indicated that they did not receive a diagnosis until after the age of three. However, 26 of the parents indicated that they tried to receive diagnosis before the age of three and were not given one. In some instances no doctor they visited had wanted to give the Autism label to a young child. Autism has been known in the past to be a lifelong disorder with very pessimistic results. Twelve of the 26 respondents did share stories about the delays that they received in receiving a diagnosis. In certain instances, parents did not receive a diagnosis because, according to the parents, the doctors did not have enough knowledge on the subject or were hesitant to label a young child, Autistic.



The breakdown, for the age of diagnosis consisted of 75 children receiving their label after the age of three. None of the respondents state that they received the diagnosis between the age of one and two. The major push today is for early intervention and many of the families I know, had personally received the diagnosis before the age of two. I attribute the differences here to the a few different facts. The first is that many of the families, I know, have young children who have just been diagnosed. Many of the children who are discussed in this study are older. The recent trend towards increased early awareness may be causing these differences. Fifty-one parents did respond in the survey that their children were diagnosed between the age of two and three. This fact was not surprising as this is becoming the appropriate age for an Autism diagnosis. Due to increased early awareness, suspected delays can be confirmed between age two and three. At this age, I believe a doctor would be more willing to make the diagnosis.

The next section of responses that were reviewed were the type of interventions that the parents were using. Most of the respondents, numbering 103, indicated that they were using Applied Behavioral Analysis with their children. Many of the parents responded that they were quite pleased with the progress that their children were making using this type of intervention. Again, many of the parents indicated that they were using additional types of therapies. The various types of therapies that were being used were:

Occupational Therapy

Speech Therapy

Physical Therapy

Secretin

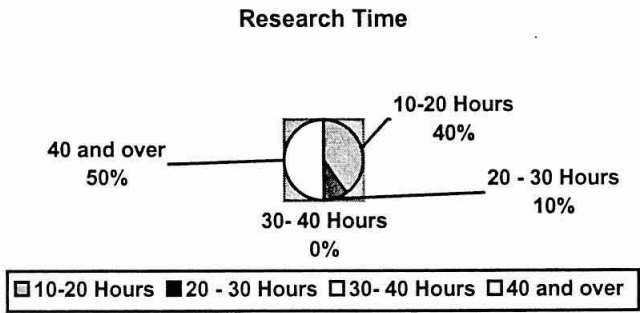
Gluten Free Diet

Vitamins.

From the overall respondents, 96 parents indicated that they had used Occupational Therapy as a supplementary intervention. Included in this number are parents who indicated they had also tried sensory integration. I combined this number because sensory integration is usually administered by an occupational therapist. Out of 126 of the respondents, 119 parents had indicated that they had used speech therapy as an intervention. Thirty-two parents indicated that they had used Physical Therapy as a form of intervention. Secretin had been tried by 42 different families, however, another 20 families indicated that they would like to try this as an intervention, but were unable to find a doctor in their area who would be willing to administer this intervention. As stated in the earlier section, Secretin is considered an off-label drug in the treatment of Autism and many doctors are not willing to help families in this manner. The total of 62 different families had tried either a Gluten free diet or mega doses of vitamins in the treatment of their children.

Finally, many of the parents explained their need to connect with other parents in similar situations. They indicated that many times they would receive help from other parents. The help they received applied particularly to the different types of treatment and interventions they were using. For example, if a parent found that their child was not learning a particular skill, they would reach out to other parents to see what they tried. Often, other parents, would be able to provide them with a different teaching technique that would eventually help their own children learn the skill. They also provided information about the vast amounts of time that they spend

researching Autism treatments. Show below, is the amount of time the parents estimate they spend researching treatments, either on the Internet, or speaking with other parents.



The actual amount of parents who spent over 40 hours per month researching was 64 of the respondents. Fifty-one parents indicated that they spent at least 10 hours researching but not more than 20 hours per month. Finally, 13 parents indicated that they spent between 20 and 30 hours per month researching on the Internet.

Many of the participants responded with more information than what can be described in charts and graphs. In many instances, they would provide attachments to their responses and some even included pictures. Some parents were responding for two children, and provided insight on what it was like to be raising two children with Autism, and the amount of time and effort required to help each child. The responses that I found to provide the most insight into the parents feelings and thoughts on Autism will be reviewed.

The first age group is the age five and under group. This group had the most responses from parents. Seventy-two parents responded in this age category providing some interesting insight.

One of the most comprehensive responses received was from a parent in Ontario, Canada. Permission was received from this parent to use copies of her child’s picture, her name and any other information that I deemed useful. Ms. Jones (not her real name) was very vocal in

responding to the survey. Her son is currently 4.3 years old and a doctor diagnosed him with Pervasive Development Disorder. Ms. Jones's response to question number three which was "How old was your child when he/she was diagnosed" is as follows:

"We suspected abnormal development (family) (sic) at 20 months. This is my first and only child. However the crime is that it took 6 months just to be seen. He was seen at approximately 2.4 months and the hospital, no under investigation by the College of Physicians and Surgeons had my son's dx for over two and a half months and feeling that Autism was SO untreatable made the G_d given decision to take 78 days from my son, not to mention the months they took to see him."

As requested by the survey, Ms. Jones also discussed the therapies she is currently using with her son. She lists the following therapies, and also, as requested, rated her satisfaction with them.

The ratings requested were 5 being the highest and 1 being the lowest. They were:

Type of Therapy	Rating	Comments
Applied Behavioral Analysis	5	Saving His Life
Vitamin Therapy	3	Has helped with eye contact
Secretin	5	Has completely remedied all symptoms of Apraxia
Acidopholis	3	Improved speech
DMG and Oxygen Therapy	4	Used to improve strength

Ms. Jones also indicated the difficulty she had with receiving a diagnosis. Since she lives in Canada, the medical system is somewhat different there than in the United States. Many times, she indicated, families have to wait, and lose precious time, before being able to see a doctor. who has knowledge of the subject. Many times, according to Ms. Jones, the doctors are extremely uninformed on the subject. In many cases, once the diagnosis is received, no information is provided about the various interventions that are available. She indicated that it has only been recently that the government of Canada has even accepted that Applied Behavioral Analysis can be a treatment for Autism.

Another interesting fact that Ms. Jones advised me of was the amount of time she spends researching Autism. She estimates that she spends at least 20 hours per week researching and teaching herself about the different therapies. She ended her original responses with the following:

“We are very out (sic) with our situation and diagnosis because we believe if we continue to hide these children away we will NEVER overcome the stigma attached to this. We feel he has nothing to be ashamed of, in fact we feel if anything Luke has a lot to be proud of. I do believe my son will overcome his Autism, and if not quite completely at least to the point where he is going to lead a full and rewarding life”

The rest of the responses from this age group were quite interesting. The majority of parents who responded were using applied behavioral analysis. One parent indicated that her child was enrolled at a public pre-school for children with disabilities. This particular parent disclosed that his/her child was diagnosed with Pervasive Developmental Disorder at the age of three years three months and has just turned four years old. As stated earlier, the child is enrolled at a public pre-school for children with disabilities and is receiving speech therapy, sensory integration therapy and specialized instruction. The parents are also supplementing the speech therapy the child receives, at school, with an additional two 45-minute sessions per week of speech therapy, outside the school. The parents are receiving support services from the school district at home and are using a Pecs system for scheduling purposes with the child. The parents, also, rate their satisfaction at a level 5 with the speech therapy the child is receiving, as well as the pre-school in which the child is currently enrolled.

Another parent responded that her son was diagnosed with Pervasive Developmental Disorder shortly before the age of four. She, currently, has been using applied behavioral analysis for her son, in her home, for about three months. She, however, spends close to 60 hours a month researching and reading about Autism.

Not one respondent stated that his or her child was receiving applied behavioral analysis in a school environment, in this age group. All the respondents stated, if they were using applied behavior analysis, it was being done in the home. One parent actually was told, “I had wanted it from day one but my son’s PPI/Early intervention staff told me lies and scared me out of doing it. After doing more research on my own I found out their statements were very false and I then began putting the program together without the aid of our local ISD”. She rated her satisfaction of applied behavior analysis at a 5 with the following quote “Because my son has changed so dramatically that I would never give up this therapy, even if it meant losing my home and all assets, it is very worth (sic) all the effort I put into making it happen for him.” She also indicated that she spent a great deal of time researching Autism, however, she did not indicate the amount of hours per month.

Another parent of a 5 ½ year old, who has been diagnosed with Autism, responded vocally as well. In response to question 4c (“If your child is receiving any type of services at home please list approximately how many therapists you have working with the child and what is their background) this parent responded with the following

“The school always selected hateful staff that did the therapy backwards. (i.e. ignored positive behaviors, reinforced negative behaviors) The staff that the school used were locals, with no education outside of high school. The people that we select are college students. We’ve found that they pick up the therapy quickly. We usually have 4 therapists working with him at any one given time”.

The following is a list of this parent’s satisfaction with the therapies that have been used along with the comments that were provided:

Type of Therapy	Rating	Comments
Auditory Integration Therapy	5	He stopped holding his ears and howling all the time. His skin was immediately less sensitive
Speech Therapy	1	Not effective
Occupational Therapy	1	Not effective
CLO (VITAMINS)	5	Much more language
SUPERNU THERA (VITAMINS)	4	Very hard to get in him, but is happier when taken
TMG	4	If he does not take this he has crying spells
Applied Behavior Analysis	4	My son has not been as successful as he could have been because the school staff undermined the programs. There have been people that we hire that he has success with and in the beginning he would work for us, until we had a "negative history" established because school therapy would carry over to home
Secretin	3	There were times it seemed to work and times that it didn't
Digestive Enzymes	4	I assume that they are helping his digestion, though there are no signs.
GF Diet	4	Though I'd suspect that this would be a five if he stopped having "wheat accidents or if I could get cheese and chocolate out of his diet
Music Therapy	4	If the college student had more knowledge about MT, I think this would be higher. He's making gains though in areas we unsuccessfully targeted in ABA

Finally, this parent stated that she spends 180 hours per month researching on the Internet and reading books. This parent, also, indicated that all therapies are paid privately and the approximate cost is \$1,200 per month.

Another interesting response came from a parent whose child is 3.5 years of age and is diagnosed with Pervasive Developmental Disorder – Not Otherwise Specified. This parent indicated that an early intervention she had used was the TEAACH method, but they stopped because “I found it did not utilize her strengths. They covered all the same items all the time and there was not data”. Her responses as to satisfaction were:

Type of Therapy	Rating	Comments
Applied Behavior Analysis	5	By utilizing her strengths listed in # 6 I felt it was the most appropriate therapy. Also, because data is taken on every drill – you know what her progress is. This also keeps us from working on the same drill through out the year.
Occupational Therapy/Sensory Integration	4	If you get a good therapist (especially private) I find that they are much more knowledgeable in the field
Diet	4	This has shown promising results. I understand there is no independent studies. However, I have seen fantastic results in areas of verbal approximations that are not prompted. Her interaction at school and home is much better
Speech	3	Need to teach therapies how to work with child in conjunction with ABA Discrete Trail Education program.

This mother also indicated that she received funding for her home ABA program, Occupational Therapy, Sensory Integration and private speech services. She pays for any additional programs that she participates in, such as the typical pre-school that she attends.

While many of the responses from the 5 and under age group were similar, the responses from the 6 – 9 group, were found to be quite varied. No one response mirrored the others. One of the responses from a parent of an eight-year old child was interesting in the range of interventions that have been tried. This child had been diagnosed with Autism, Landau-Kleffner Syndrome, Childhood Disintegrative Disorder and Obsessive Compulsive Disorder. This parent had been using the TEAACH, and the “floortime” method for the past three years. The main environment in which the child received this intervention was in school. The parent still spends hours researching different interventions on the Internet. Listed below are the interventions that have been used and the parent’s satisfactions. They are:

Type of Therapy	Rating	Comments
Floortime	5	None
Physical Therapy	5	None
Occupational Therapy	5	None
Speech Therapy	2	None
TEAACH	3	Would like more relationship programming

As with the parents from the other age groups, this parent spends every free moment either on the telephone talking to other parents, or on the Internet researching different interventions for the child.

Another respondent to the survey listed some information that varied from many of the others that were received. The family indicated that Autism was the diagnosis, but, also, indicated that the original diagnosis was Pervasive Developmental Disorder-Not Otherwise Specified. This child the child is currently in a self-contained classroom for autistic children and

has been using a Pecs schedule system since the three years six months of age. What I found interesting is that this parent indicated that the child has a 1:1 aide when he participates in the regular classroom, which is about twice a week. This parent lists PECS as the only type of therapy the child is receiving and rates it at a 4 in satisfaction but states “ We decided on the original therapy (PECS) because it was what his special needs preschool teacher recommended, and what she was experienced with. We also figured out that our son was very visually oriented. He has progressed well, however, slowly, over the years. More speech, more focused, great eye contact.” Again, this parent states about researching, “Yes, always researching different ways to help him. Spend at least 1 – 3 hours every day on computer; read books/journal articles when available or they pertain to treatments, etc. On an average, I would say I spend about 40 –50 hours per month researching or reading.”

Another family who responded in this age category, had interesting statements related to the long-time usage of applied behavior analysis. This child was diagnosed at two years of age and is currently 7 ½ years old. He had been using ABA since the child was 2 ½ years old. This child is currently participating in full-time inclusion with the assistance of a 1:1 full time aide and is using a forty-hour per week program at home. This parent indicates that the first 3 years of ABA were executed wrong, and this was due to the consultant providing incorrect advice.

This parent's interventions and satisfaction ratings are listed below. They are:

Type of Therapy	Ratings	Comments
Applied Behavior Analysis	3.5	My son isn't having much spontaneous language even after these year, but I think we were doing (I know we were) wrong for 3 of the 6 years because of the consultant
Speech Therapy	3.5 – 4	Getting better because therapist is trained in ABA tech.
Occupational Therapy	4.5	Private OT is ABA trained and knows how to cue into sensory issues. School OT is helpful in certain ways but he is 1 of 42 caseload. Not trained in specifically in areas we need.

This parent also states that she have tried other therapies such as Secretin, dmg and supernuthr, but did not see enough of a change to continue with these types of interventions. Again, this parent estimates that she spent about two hours per day on the computer keeping connected with other parents and reading new information that comes up. This parent also indicates that she is currently researching diet as a new intervention to try. Finally, she does indicate that she receives full funding for the forty hour per week program, but if it goes over the forty hours per week, in most instances, she would have to pay those costs out of pocket.

The last age group was children aged nine and over. This area brought many of the same responses as with the younger groups. One response was from a parent whose child was diagnosed with Asperger's Syndrome. This child is currently 12 years old and was not diagnosed until the age of 6. This child is currently, according to the parent, entirely mainstreamed in school. The services this child receives are speech and language, social skills

training and anger management training. The therapy is mostly administered by the parent since she lives in a rural area. She indicated, he/she received services from a local university for the anger management, and that the child also has apraxia, which is a speech articulation disorder. She also, indicated that she is very pleased with the behavior trainer and speech therapist that she uses. She rates them at a five, but all the school personnel, who are working with her child, are all rated at a one. She indicates that her local school board had never had a child with this disability before and she had to spend many hours providing them with the research to obtain the necessary services that her child needs. She indicates that she has "Clocked up thousands of hours since he was diagnosed". Also, written on her survey was that she has private insurance that picks up most of his therapy costs and then Medicaid picks up the balance .

One of the more inspirational quotes came from a parent whose child is currently 9.8 years old and is diagnosed with Pervasive Developmental Disorder, Anxiety Disorder and Attention Deficit Hyperactivity Disorder (ADHD). This parent has her child enrolled in an applied behavior analysis school during the day from 8:30 – 2:00. She indicates she has been using ABA for 4 years. She writes,

"When my daughter was diagnosed, I spent over 100 hours in a medical library researching Autism and the treatments that were available at that time. I felt that since I knew my child best, I would make the determination on what treatment plan would work best for her. I chose ABA and I've never regretted my choice."

This mother went on to indicate that both she and her husband will do whatever it takes to help their daughter. She stated that her husband is currently working three jobs, that entail 70 hours per week, and that she works, when her children are in school. She, also, made it clear that she is quite proud of what her child has accomplished. She states that she is currently in a girl-scout troop with all typical children. She suggested that four years ago her daughter would not play with anyone and now girls from the troop come over and play at the house with her,

regularly. She, also, participates in a religious education class with 20 other children. The parent stated that her child's expressive language is above age level and her receptive language is below age level but they are working on that issue as well. She did indicate that she spends at least ten hours per week researching "new treatments, therapies, diet interventions, homeopathic interventions each week."

The oldest child whose parent sent a response will be 13, on May 16, 2000. This parent indicated that she had many different diagnosis before the age of five. According to the parent, at age 2 the child was diagnosed with an expressive language delay. At age three, it was possible PDD, at age 4 was told – "OK, I guess it might be PDD but he's definitely ADHD," and, finally, at age 5 told by teacher that she thinks he has Autism, but so does her son. This parent returned to the neurologist at age five, and he still indicated that it was PDD with ADHD. While this parent has tried many of the previous discussed interventions, she was the only parent who indicated that her child was on a prescription drug. She mentions that he is on ritalin and could not be successful in the classroom without it. As many of the other parents, this parent is still spending at least twenty hours per week on the Internet and helping out at the local Autism Society of American chapter.

Chapter Five – Conclusions

Overall, the responses sent provided insight into what methods parents are currently using to help their children. Shown below is a graph that outlines a summary of the responses received from parents.

Age Group	Number of Respondents	Primary Intervention		Time Spent Researching			
		Type ABA	Other	10-20	20-30	30-40	40 & Up
Age 5 and Under	72	100%	0%	40% (28)	20% (14)	0%	40% (30)
Age 6 – 8	19	80%	20%	10% (2)	0%	0%	90% (17)
Age 9 and over	35	90%	10%	80% (28)	10% (6)	0%	10% (8)

There are many observations that can be drawn from the responses received from parents who participated in this survey. The first, is the amount of time each parent spends researching the various treatments for Autism.

Most parents who responded stated they spent 10 hours or more per week researching this subject. I feel that the implications for teachers and educators are quite important. If we have Autistic children in our classrooms, we can assume that the parents may be spending many hours researching different methods to help their children. As educators, we should try and determine if the parents are spending much of their time researching on the Internet. If they are, and upon determining the knowledge level of the parent, we should attempt to be respectful of the suggestions the parents make. If they are knowledgeable, we should take their suggestions, readily, in regard to the teaching strategies that may work with their children. In addition to the knowledge that they have gathered from various sources, they, as parents, will have extensive knowledge of the children's strengths and weakness. They might be working with the children at

home, and may be able to share with you information such as how the children learn best, i.e. strong visual learner. This information, when received at the beginning of the school year can help in many areas. One area that the knowledge from the parent can help is in seating placement of the children. A child who is known to be a strong visual learner should not be placed at the back of the class. He/she should be placed where he or she is close to all academic visual stimuli that will be presented.

The teacher should be aware of whether or not the child tends to be distracted by various sounds. You can use this information received from the parent, and, again, place the child away from outside sounds which can compete for the child's attention. Many times, you can get all this information from a parent of an Autistic child. Obtaining this information from the parent, as close to the beginning of the school year as possible, will help make this a successful year for the Autistic child.

Another aspect that can be drawn from the responses received from the survey is that very few parents are relying on one intervention for their children. The majority of parents who responded are using more than one type of intervention and there are many different types of interventions. Many have tried Secretin, and, it was found that the respondents did not have as high results as had been reported in literature and the media. According to the various sources reviewed earlier, this had appeared as a very promising treatment. Apparently, according to the respondents in my survey, this is not the case. Interestingly enough the one respondent who did indicate that she had had very good results with Secretin had it in the area of apraxia, not Autism. This parent responded that Secretin treatments had eliminated the child's symptoms of apraxia.

Many parents also indicated that they did not continue with the Secretin injections because they felt the risks were outweighing the benefits. I believe that many parents do not

want to risk the use of an “off-label” drug, and its implications, if it is not producing incredible results for their children. As with all drugs, there are dangers and risks.

I, also, believe that this brings up an interesting concept that should be focused on. There was a period of time, approximately two years ago, where all those involved with the treatment of Autistic children were discussing Secretin as an intervention for Autism. Some professionals even felt that this might be a possible cure. Many families “jumped on the bandwagon” and were pressuring their doctors to administer Secretin to their children. Many of these parents wanted to believe, so badly, that this would help their children, that they forgot that this was a medical intervention that had not been tried on many children. I believe, as the results of this survey indicated, that if we had sent this out a few years ago many of the parents may have responded quite differently. This group of parents did not have the promising results that had been so widely publicized in the media. It should be noted that, as educators, we should remember to advise these parents that when new treatments “come on the scene” they should take the time to evaluate the procedure. They should carefully weigh the risks that are associated with the new treatment. I believe that parents of children with Autism are often searching, desperately, for a cure, and need to be gently reminded that there are no “overnight” cures.

Others had indicated that they had tried Sensory Integration Therapy. Many indicated that certain symptoms associated with Autism had been reduced by the Sensory Integration Therapy. This information could also help a classroom teacher if it is provided to them. If a child has certain sensitivities that have been eliminated in therapy, the teacher could be more sensitive to these issues. This is another factor that can be used by educators to help the children. If a child has been known to have sensory issues in the past, an educator may not want to seat them underneath a bright light as they might be sensitive to the lighting. If a parent indicated

that loud noises, in the past, had bothered the child, the teacher would be able to seat him/her somewhere in the class that was not subject to these noises. Sound frequencies are another issue that are sometimes eliminated in Sensory Integration Therapy, and if the child has successfully gotten over this part of their disability the teacher should be aware of this. Consequently, a certain sound might be an antecedent for a certain behavior of the child. Again, depending on what grade you are teaching and the amount of mainstreaming the child has had in the past, this might be the first experience the child has had in a particular type of classroom. Consequently, issues that the parents and previous teachers may have thought were under control may come to surface again, depending on the environment. With the prior knowledge of the sensory issues, the teacher may be better able to assist the child in returning to task.

I did find the fact that so many parents had success with this intervention to be surprising. In much of the literature that I have read regarding Sensory Integration, I had not thought this would be such a popular intervention, with parents. Not only did I find the popularity surprising, but, also, the fact that the parents felt it had helped their children so much.

Other parents indicated that their children were on special diets. This is very important knowledge for a classroom teacher to have, and an important question for the teacher to ask. If they are on special diets, teachers need to know, so they do not inadvertently give the children a food that they are not allowed to have. This holds true for all students since some have allergies of which the teacher must be made aware.

Another implication that can be drawn from the results of this survey, is there is widespread disagreement between parents and educators on what is best for the children. I believe this is an area of critical importance. As educators, we must learn to respect the knowledge the parent may have about the child's disability. As shown earlier, many of the

parents of Autistic children spend hours and hours on end learning about this disability and how they can help their children. Parents and educators really need to work as a team to have the best outcomes for children. I have learned from journals, Internet List-servs and books that the children who have the best outcomes are those whose parents and teachers work together to coordinate the services the children are receiving. In instances where a child has a home program and is in school, communication is vital to that child's success. Parents, Teachers, and Home Therapists need to set up communication journals, early on, so that what is being worked on in school can be relayed home to those working at home. Consequently, when communication is successful the child does much better. Each party can reinforce what the other is doing and achieve the desired results quicker. Meetings between the different parties are also a critical factor in the success of these children.

Also, as indicated in the literature review, no one method is going to work with each child. However, the parents may have already tried many of the different methods with their children and may be able to suggest a strategy that will help them. If a child is acting out, at a certain time each day, and, if the teacher has tried to determine what is causing this behavior and is unable, they must contact the parents. They may be able to tell you what causes it and how to have it decrease. The parents can be an invaluable source of information in the management of their children. In most cases that I have seen, parents of Autistic children want to be involved in their children's education, and would jump at the chance to help the children achieve higher levels of functioning.

The literature review did provide samples of the many different educational options that are currently available to parents and educators. As educators, if we are presented with a student who is Autistic in our classroom we should be aware of the different types of

interventions that are currently used. Loovas or ABA was the most popular in teaching techniques among the parents surveyed. This was not as surprising as much of literature today is based on the success of ABA. Catherine Maurice's (1996) two books, one that dealt with her children and the other which outlined ABA programs for families, have helped the popularity of ABA. While I do believe this is a very effective way of teaching young children with Autism, I, also, believe that any method that is found to work with the individual children should be used. The higher level of functioning each child, with Autism, can achieve, the less of a burden on society this child will be in later life.

I was, also, surprised at the lack of parents who mentioned the TEAACH method. Out of all the respondents of my survey, only one mentioned this method of teaching as being currently used with her child. The parent also indicated that her satisfaction with this type of intervention was on a 3.5 level. Many of the discussions on the list serv's that I participated in, focused on the differences between ABA and TEAACH. I do know, Palm Beach Country currently uses the TEAACH method in their classrooms. I should note that in addition to using TEAACH they also incorporate the use of PECS to enhance speech and language development and work on skills in a discreet trial format.

I believe this project answered the questions it set out to answer. The first question was to determine what researchers are currently saying about Autism. I found that the literature stated that early intervention is critical in the long-term success of the child with Autism, as was shown in the information provided by the May Center and the UCLA Project for young children with Autism. Identifying children as early as possible is a critical factor in the long-term success of children with Autism. What this project found, is that many parents did not receive the official diagnosis until their children are passed the early intervention stages. I believe that in

order to help children with Autism much more needs to be done in reaching parents whose children might be effected. Project Child Find, as it is known in Florida, needs to be expanded so that pre-schools can be advised and trained as to what are the early warning signs of Autism. Pediatricians need to be advised, as well, so that they don't mistakenly give a parent reassuring information when there really is a problem. The current information needs to be provided to all of these parties, so parents know early on that a diagnosis of Autism is not the "death" sentence it was ten or fifteen years ago.

Also it was found that the majority of parents were using the Applied Behavior Analysis method and that this has produced high gains for those children. Many parents are embarking on high cost and stressful programs for the children, and others, in the family. While these are impressive gains, we, as educators, need to be aware of the toll it can take on these children. Educators need to be aware that there still needs to be a balance for these children.

Many parents are also using alternative therapies. As the name implies, they are just that, alternative to the basically accepted therapies. What was found in the research, and in the answers of the respondents of the survey, was that for some children they produced gains but not for others.

This project, also, set out to determine what the parents were actually implementing at home. I found that many parents were administering home programs in conjunction with school programs, trying various diets, and experimenting with Secretin, but most importantly, they are constantly researching and looking for ways to help their children. Again, the implications here are important because, as educators, our most important resource, in helping children with Autism, could be the children's parent.

Teachers should try and maintain open communication with the parents. We need to remember that no matter how many gains the Autistic child has made, the parent still lives with this disability day and night. We need to remember that they still are parents who have feelings regarding their children's disability. Maintaining this open communication with the parent cannot only help, us as educators, learn more about the disability, but more importantly, the information gained from the parent could make the difference in the child's learning and life.

Finally, I had many hopes for this project. I had hoped this project would help educators teach children with Autism. I wanted educators to learn that there are different interventions that can help children with Autism today and that they can work with families to increase the likelihood of success for the child with Autism. It is important to note that research on Autism today is very different from the research on Autism of five years ago. It still is a commonly misunderstood disability. To quote the Autism Society of America

“Over one half million people in the U.S. today have Autism or some form of pervasive developmental disorder. Its prevalence rate makes Autism one of the most common developmental disabilities. Yet most of the public including many professionals in the medical, educational and vocational fields, are still unaware of how Autism affects people and how they can effectively work with individuals with Autism.”

It is my desire for this paper to increase awareness for both educators and parents. It was my hope that this paper through the compiling of current information about Autism would enable educators and parents to have a starting point of reference. As Ronald Anthony stated “A point of reference is the most sought after point in life”. I hope this paper can be a point of reference for parents whose children have just been diagnosed with Autism. I want them to be able to go to one source and find valuable information and provide them with sources to obtain additional information. I want parents to know there is hope for their children, and, there are interventions that will help their children to have productive lives. When a parent first receives the diagnosis

they have hundreds of questions. I hope that this project answers some of their questions and, again, provides them with comfort in the fact that they are not alone and help is available for their children.

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APPENDIX A:

DR. BAKER'S RESULTS OF THE USAGE OF SECRETIN

Average Number of Patients Showing Symptom Magnitude Changes, per Wee
Symptom

n = 48	Week 1		Week 2		Week 3		Week 4		Week 5		Week 6		Week 7	
# of patients w/ symptom - symptom	impr.	regr.	impr.	regr.	impr.	regr.	impr.	regr.	impr.	regr.	impr.	regr.	impr.	regr.
Social Behavior - Average	8.3	-	4.6	1.3	5.8	0.5	3.6	0.5	3.1	2.4	4.9	1.1	2.6	0.9
39 - Lack of awareness or inattention to others	15	-	2	3	6	2	2	-	3	4	7	2	4	1
37 - Absence of joint attention or sharing of interest	15	-	6	3	9	1	2	1	2	3	6	2	3	1
38 - Abnormal greeting behavior	8	-	8	3	9	-	2	-	3	3	7	1	4	1
29 - Abnormal comfort seeking	4	-	3	-	6	1	5	1	2	2	3	2	3	2
40 - Impaired social imitation	11	-	6	1	4	-	6	1	2	1	5	1	2	-
37 - Cannot make friends	6	-	3	-	2	-	3	1	5	2	4	1	2	-
34 - Impaired pretend play	5	-	2	-	4	-	6	-	3	2	3	-	1	1
44 - Lack of awareness of social rules	2	-	7	-	6	-	3	-	5	2	4	-	2	1
Communication - Average	8.5	0.2	3.7	1.5	4.3	0.2	2.8	0.3	2.5	0.8	3.0	1.0	1.5	0.3
39 - Lack of spontaneous speech	11	-	5	2	7	-	2	-	3	1	4	1	2	-
32 - Abnormal word utilization	8	1	2	1	6	-	1	-	4	1	4	2	2	-
42 - Poor comprehension	15	-	5	2	5	-	4	-	2	1	4	-	1	1
30 - Bizarre speech patterns	5	-	4	1	5	-	3	-	1	1	3	1	2	-
39 - Impaired pitch/stress/rate/volume/rhythm of speech	9	-	5	3	3	1	4	2	5	1	2	1	1	1
32 - Impaired expression of abstract symbols	3	-	1	-	-	-	3	-	-	-	1	1	1	-
Ritual or Repetitive Activities - Average	3.4	0.4	4.3	2.0	5.3	1.9	3.1	0.9	3.6	2.3	3.9	0.7	2.0	2.1
36 - Motor stereotypes	2	1	4	3	4	6	4	2	4	3	5	-	2	3
39 - Abnormal sensory or motor behavior	6	1	6	2	4	3	6	1	4	4	5	1	3	3
33 - Preoccupation with objects	1	1	3	1	4	2	1	1	4	3	4	-	4	1
34 - Need to maintain sameness	2	-	6	1	6	1	3	-	2	2	4	1	2	2
32 - Fixed routine	2	-	3	1	5	-	2	-	1	2	3	-	1	2
42 - Restricted and/or perseverative interest	3	-	5	2	6	1	2	1	5	2	3	-	1	2
35 - Absence of spontaneous interest	8	-	3	4	8	-	4	1	5	-	3	3	1	2
Digestive - Average	5.0	2.0	5.5	1.7	3.2	0.5	1.3	2.0	1.2	1.7	1.7	1.7	1.2	1.3
24 - Diarrhea	5	6	9	2	5	2	3	4	4	4	5	3	2	4
16 - Constipation	5	-	1	3	4	-	-	4	1	2	-	3	2	1
18 - Poor appetite	5	1	6	1	1	-	1	2	-	1	3	-	1	1
17 - Bloating	5	-	4	1	3	-	-	-	-	2	-	1	1	-
24 - Farting	6	2	7	2	4	1	3	-	2	1	-	1	-	2
14 - Abdominal pain	4	3	6	1	2	-	1	2	-	-	2	2	1	-
General - Average	7.5	2.2	4.3	3.0	4.5	2.8	3.7	2.2	2.5	2.5	4.3	2.2	3.7	2.0
28 - Unhappy	7	-	6	3	4	1	-	4	1	4	6	2	3	4
28 - Aggressive	5	5	3	2	5	3	3	2	3	3	5	2	4	1
22 - Destructive	2	2	3	2	1	2	4	-	1	2	2	2	3	1
42 - Spaciness	16	2	6	4	6	2	5	1	4	3	5	-	4	1
37 - Agitation	11	2	3	3	6	5	5	3	2	2	4	3	5	2
33 - Disagreeable	4	2	5	4	5	4	5	3	4	1	4	4	3	3
Overall Averages	6.5	1.0	4.5	1.9	4.6	1.2	2.9	1.2	2.6	1.9	3.5	1.3	2.2	1.3

Number in symptom label shows the number of patients with that symptom. This table show the count of patients changes per symptom per week. **Interpretation:** Most of the changes occur early in the earlier rather than later an behavior and communication were the areas in which the most improvement was reported.

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summary data

Summary of Group Symptom Changes from Baseline to the Seventh Week after Receiving a Secretin Injection

This summary data show that the symptoms in which the group scores show the greatest improvement are digestive symptoms in general, spaciness, lack of spontaneous speech, absence of joint attention of shared interests, and abnormal greeting behavior. Note that the digestive changes appear to be the best, but there were fewer children reporting symptoms in this area (mostly because many of these children had already be under other treatments that had resolved the digestive problems that are so common in autistic children.)

The table shows both the symptom magnitude score increase or decrease and the percentage of change from the baseline score through the seventh week after the secretin injection for the entire group. Symptom scores range from 12 (incapacitating) to 1 (very mild). * Not all patients had all symptoms. A positive number means the symptom abated or improved; negative numbers mean the symptom became more severe.

* Note: Lower scores in this column indicates improvement.

n=105; females=20; males=85	Baseline Group Average	* End of Week 7 Group Average	Average Symptom Improvement	% Symptom Improvement	# w/ t Sympt
Average of all Symptoms	5.94	5.00	0.94	0.16	
Social Behavior Symptoms Overall	6.80	5.83	0.98	0.15	
Lack of awareness or inattention to others	5.66	4.59	1.07	0.19	
Absence of joint attention or sharing of interest	6.64	5.48	1.16	0.17	
Abnormal greeting behavior	6.08	4.99	1.09	0.18	
Abnormal comfort seeking	4.64	3.99	0.65	0.14	
Impaired social imitation	7.19	6.14	1.05	0.15	
Can't make friends	8.06	7.24	0.82	0.10	
Impaired pretend play	8.16	7.14	1.01	0.12	
Lack of awareness of social rules	8.01	7.09	0.95	0.12	
Lack of spontaneous speech	7.95	6.73	1.22	0.15	
Communication Symptoms Overall	7.09	6.36	0.69	0.11	
Abnormal word utilization	7.28	6.42	0.85	0.12	
Poor comprehension	6.18	5.29	0.90	0.14	
Bizarre speech patterns	6.84	6.11	0.73	0.11	
Impaired pitch/stress/rate/volume/rhythm of speech	6.88	6.19	0.58	0.10	
Impaired expression of abstract symbols	8.27	7.80	0.41	0.06	
Ritual or Repetitive Activities Symptoms Overall	5.79	5.20	0.56	0.10	
Motor stereotypes	6.13	5.73	0.30	0.07	
Abnormal sensory or motor behavior	6.20	5.67	0.52	0.08	
Preoccupation with objects	5.79	5.23	0.57	0.10	
Need to maintain sameness	5.32	4.76	0.51	0.10	
Fixed routine	5.02	4.47	0.49	0.11	
Restricted and/or preverbal interest	6.24	5.55	0.67	0.11	
Absence of spontaneous interest	5.82	4.97	0.84	0.15	
Digestive Symptoms Overall	4.78	3.39	1.31	0.30	
Diarrhea	4.82	3.35	1.41	0.30	

Constipation	4.72	3.31	1.37	0.30
Poor appetite	5.55	4.40	1.06	0.21
Bloating	5.25	3.70	1.44	0.30
Farting	4.28	2.94	1.22	0.31
Abdominal pain	4.08	2.64	1.35	0.35
General Symptoms Overall	4.12	3.41	0.72	0.17
Unhappy	3.12	2.75	0.38	0.12
Aggressive	3.58	3.02	0.57	0.16
Destructive	3.69	2.88	0.78	0.22
Spaciness	5.34	4.12	1.27	0.23
Agitation	4.74	4.01	0.79	0.15
Disagreeable	4.25	3.66	0.57	0.14

Preliminary analysis of secretin response n = 39

Change in the symptom magnitude scores per symptom of patients with an overall negative response to secretin. The tabulation is simply the baseline score (pre-secretin score) minus the 7th-week score.

Positive Numbers indicate Symptom Magnitude Increase. **Blanks** indicate **no change or not a symptom**. **Negative Numbers** indicate Symptom Magnitude **Abatement**.

Note that a significant change in one symptom can skew the overall results.

Symptoms were rated on a scale of 1 to 12, with 1=mild and 12=incapacitating.

Sex	m	m	m	m
Age at 1st injection	5.0	9.5	7.1	8.7
Weeks	wk7-base	wk7-base	wk7-base	wk7-base
Lack of awareness or inattention to others	-0.5	2.5		
Absence of joint attention or sharing of interest	-0.5			
Abnormal greeting behavior	-5			
Abnormal comfort seeking		-1		
Impaired social imitation	-5	-2		
Can't make friends	-3			
Impaired pretend play		0.5		
Lack of awareness of social rules	-5	-1		
Lack of spontaneous speech		-3		
Abnormal word utilization	-3			
Poor comprehension	-3	-1		
Bizarre speech patterns	-3	-1		
Impaired pitch/stress/rate/volume/rhythm of speech		1		
Impaired expression of abstract symbols	-3			
Motor stereotypes		2	1	
Abnormal sensory or motor behavior		4.5	1	
Preoccupation with objects				
Need to maintain sameness		-1		
Fixed routine				
Restricted and/or perseverative interest		1		
Absence of spontaneous interest				

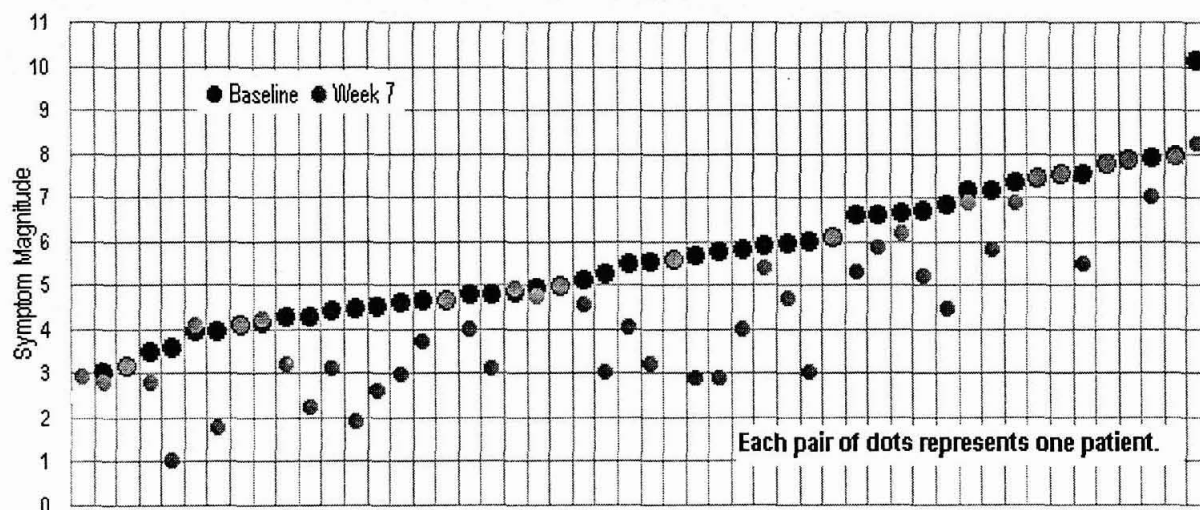
Diarrhea				-3
Constipation				
Poor appetite				
Bloating		-3		
Farting	3			
Abdominal pain				
Unhappy				
Aggressive				3
Destructive		1		-3
Spaciness	-3	-0.5		-3
Agitation				-3
Disagreeable		1		-3

preliminary analysis of response to secretin, graph one

Annotation can be found below the graph.

**Change in Average Symptom Magnitude Scores, by Subject,
Before Treatment and After the Seventh Week**

n = 50, t = 7.29, significant at the p = < .001 level



This graph shows 50 individual children's average symptom magnitude scores (0=none, 3 = mild, 6 = moderate, 9 = severe, 12 = incapacitating) at baseline (blue dots) and at the end of 7 weeks (red dots) post-secretin injection (75 CU per child). **Interpretation:** Most of the children receiving secretin reported some improvement as reflected in an average of all reported symptom scores. This represents about 71% positive response rate.

We ran a correlated sample t test to determine if there was a significant difference between the means of the baseline and average of the scores of weeks one through seven. There was one less observation since we eliminated a subject with incomplete data between weeks one and seven.

t-Test: Paired Two Sample for Means		
	Baseline	Average of Weeks 1 through 7
Mean	5.58	4.72
Variance	2.51	2.98
Observations	49.00	49.00
Pearson Correlation	0.85	
Hypothesized Mean Difference	0	
df	48.00	
t Stat	6.50	
P(T<= t) one-tail	0.001	



The null hypothesis is that there is no difference between the means of the scores (that the treatment had no effect). There is a significant difference between the means for each of the tests, more significant if just the final week scores are used.

The caveats are that the data isn't "clean," meaning variables other than secretin could be acting on the scores. The subjects are a select group and were not a random sample. There is no control group for comparison. It is not a true experimental design but rather a *post hoc* data-gathering instrument.

In this case, the t test can be used as a descriptive tool only, highlighting that there may be something significant going on that merits further investigation. Which it does. The treatment is having an effect, whether it's the secretin alone or acting in concert with other treatments remains to be investigated.

APPENDIX B:

LIST SERV RULES

Subscriber Rules For The Autism List

Introduction

Membership in this list is a privilege not a right! This is not a free board for people to peddle their philosophy or belief. This list was formed by an owner who has every right to setup and enforce rules and every right to eliminate those who will not abide by the rules. My belief is that when you try to push your opinions and beliefs on other people that is an infringement of their rights and I will not abide by that. Nor will the excuse of breaking the rules that you think it is important. While there may be important topics that may be banned by the rules, to keep the sanity of this the topics have been banned. If you feel the need to express your opinions find another forum or start one of your own.

This page/sheet sets the rules for participation in the Autism List that is located at St. Johns [REDACTED]. Every subscriber should be aware of these rules and will be responsible that each of their posts abide by these rules.

At one time this list did not have any set rules, however complaints, flames, personal attacks and sarcastic posts have shown a need for them. Some of these actions have caused people who were badly in need of support to leave the list. Since that is the purpose of the list the rules are created to assure this list will be a comfortable place for all subscribers. A way of dealing with people who post content not in conformance with the rules is also needed and is set by these rules.

NOTE: These rules were not derived at lightly, nor were they for the listowners to block topics or views they did not agree with, they were derived to make the list a useful tool for people who need support.

These rules may be updated at times as The Panel Of Listowners deem necessary. No prior notice to the populace need be given and the rules are in effect as soon as they are announced. New rules and changes to rules are not open for discussion on the list. If you have a problem with them contact the panel of listowners.

Panel Of Listowners

The handling of setting of rules, reacting to complaints, and taking care of new subscriptions, will be performed by a panel of 3 to 4 listowners. (From here on referred to as the "Panel"). Their duties will also include assisting subscribers with listserve commands and possibly handling of bad mail. Bad mail is handled automatically by the listserve. However occasionally a subscriber will need help in solving addressing problems with email and the Panel will also help with that.

Since I formed the list I will be one of these members of the Panel. For the record I am a parent. I set the list up to support families with difficulties in dealing with issues with special needs and for the purpose of sharing information and helping locate resources. It's main direction has always and I hope will always be to support people and to provide information to gain access to needed resources.

The Panel will consist of volunteers in the following categories:

1. A parent of a disabled child (preferable with autism or a similar developmental disability).
2. A professional such as a teacher, administrator, therapist, counselor or anyone who works daily with the disabled or their families.
3. An Autistic or similarly developmentally disabled individual.

In the event there is not a volunteer from one group the position may be filled with a person from one of the other categories.

Methods of replacement of leaving panel members will be decided by the Panel Members at the time of the need.

Posting Rules

Respect for all subscribers is paramount

On this list, We all have the right to be respected. As stated above, membership in the list is a privilege not a right. Parents are under constant pressure dealing with school districts, professionals who are trying to help their children, seeking services for their children and trying to keep their day to day life somewhat intact. Professionals are often under pressure to use methods and techniques which they have not been sufficiently trained for but have been directed to use. Autistics constantly have to deal with the stresses daily life puts on them as well as the issues of a society that is not often very supportive of autistic issues.

The professionals on this list are on here for a number of reasons. One, to learn from those closest to the situation, what living with special needs means on a day to day basis. Two, to offer support on programs, therapies or services they may be expert or familiar with. While it may be an economic advantage to these people, they are here to help us in case people want more details about their expertise. Their programs may be controversial, they may not work for all, but once again they are here to help parents and autistics who may want the information these professionals may have. However, note that this also is not an advertising board for your products. Too many pushes of your product can be viewed as inappropriate use of this list.

The autistics are on the list for fellowship with other autistics or other people in general and because they have very valuable experience to pass on to all of us. They can offer a unique inside view that all of us have a need to understand.

No one on this list needs to be challenged by others on this list. Being told their parental abilities are poor, or that the program they are using is wrong or they are negligent are all forbidden. The purpose of the list is to offer support and ideas to other subscribers, not to belittle them. If you can't offer support or helpful ideas, you should not offer anything. This applies to all subscribers, parent, autistic or professional. All of us have something to offer and have a place on this list and are not to be ridiculed, criticized or replied to with sarcasm.

Topics Banned

Our tendency in managing the list is to ban as few topics as possible as they relate to Autism. We also do permit non-Autism related posts so long as they are not taking up the bulk of the email. Please be considerate with non-Autism posts and with humor posts, put something in the "Subject" line of your post, such as "Off-topic" or "Humor" and keep them decent and brief.

The topics we do ban are not because the list owners have a preference in the issues, it's usually because the topic is too controversial and will for sure detract from the useability of this list.

Currently the only topic banned on this list is the subject of Abortion. It is banned in any form, regardless of how it relates. This is too hot a topic for this list, too often it has completely dominated the list when it has been brought up. This is too often a religious decision or a decision with the same reasoning as religion. It hasn't been decided elsewhere despite protesting, panel discussions etc. And likewise it's discussion on this list is not likely to influence people's belief regarding abortion. If you feel the need to discuss this then find a different forum. It will be a banned topic in any form, including forwarding publications or email bulletins which include the topic.

This is the only banned topic. However that doesn't mean we might not ban another discussion if it becomes too hot. If so we will notify and then the populace is to drop the topic or pay the consequences.

Guidelines for discussions of topics:

I find that some guidelines for discussions are necessary, to prevent exchanges that are serving individuals interests rather than serving all members of the list.

In the past on this list and others I've seen topics beaten to death with tactics such as mudslinging and outright intimidation of other people's opinions. I can name ABA, FC and a few others. Where certain parties didn't believe in a method or treatment and felt it was their duty to discredit it. On the other hand I've seen it used in the reverse to intimidate people into using a therapy or treatment, either by belittling other methods or by implying that to fail to try a treatment is child neglect. In almost all of these cases these people started discussions that ruined any useful discussion of the topic.

I will not allow any such discussion like that on here at all. While the wording of such a rule may not be able to be too specific, the intent can be quite clear. The Listowners will open complaints if they see such tactics and they will honor any complaints sent to us on this matter.

If you represent an organization that fosters a treatment or policy in relation to Autism or you feel strongly about such a group, the discussion must carry on describing the benefits of the treatment or policy you are advocating. If you or the organization you represent, or are involved with, also advocate the belittlement of another organization or treatment, that side of your organization is not welcome here. The parents on this list are intelligent people who can figure things out themselves by what they see and hear and the results they see. Discussions of the validity of proofs are not appropriate for this list, take them to a professional list.

Once again, the purpose of this list is to help people find resources, not to advocate particular ones or to discredit others. Advocacy of a treatment, policy or organization must take a positive attitude (discussion of benefits), not a negative one (discrediting of other therapies etc. in favor of what you advocate). Discussions of these treatments etc. must never include names of other subscribers.

To be more exact I don't want to see any battles with one organization bashing another. Likewise if anyone is a member of an organization I see no need for discussion of that on this list unless they themselves bring it up in an effort to help someone. Present the positive things regarding your organization, not the negatives of other organizations.

Please also remember that when heated debates start up, think of the rules. If something looks like a flame war starting, do not join in, flame wars are extremely forbidden.

If you see such a discussion beginning, do not join in with it, if you just jump in on bashing, such as "You Go Girl!" or "You tell him", you will be considered an accessory of the breach of rules!

In all discussion on this list, keep posts and responses civil or keep them to yourself. If someone else gets uncivil, do not respond, instead contact the Panel and ask for a complaint to be lodged.

Program Plan and Methodolgy Discussions

Discussion about programs and methodologies are permitted so long as they continue to be about the program or methods rather than the poster or other listmembers.

Some topics tend to be controversial and generate some heated discussion. If arguments get too heated and yet they are reasonable one of the Panel may ask for a two or three day recess, where parties halt discussion for a set number of days in hopes of cooling off discussion, and come back to the discussion in a set number of days.

Posts which begin to be directed at the poster more than the topic will be considered in violation of the rules. The Panel may step in and take action, especially where the Panel begin receiving complaints from subscribers.

REMEMBER! Despite how a program, therapy or treatment works for you does not mean it will work for every child or person. If a parent choses to use or not to use a certain treatment or therapy on their child it is their business only.

Posts that lead people to believe that they are being negligent or abusive if they do or do not use a specific therapy or treatment are considered in violation of the rules.

It is fine to relate your experiences with a therapy or treatment but it is a violation of the rules to tell them they are doing something wrong.

If you think that some other plan or treatment is better you may offer them a suggestion with an offer of more information via private email if they are interested. If other people are also interested they may request it posted public and you may post it public.

Regarding Subscribers who have Products or Services to Sell

People may subscribe who are either commercial suppliers of products related to Special Needs or people who have an interest in Autism but also may have some product or service to sell.

No one on the Panel of Listowners support/benefit or endorse any of these products. I allow them because some subscriber(s) may have a specific need for these products, and it may be the easiest way for someone in need to find the resource.

However the following stipulations will apply. No routine daily/weekly/ monthly advertisements on this list. Contact information and a brief description of what you sell may be sent out in a reminder, however no more than once weekly unless requested by a subscriber or Panel Member.

Anyone who has received an unsolicited advertisement from any commercial subscriber and wished to lodge a complaint against the commercial subscriber may send that complaint to the Panel of Listowners.

Membership on this list is not to be considered an indication of an interest or invitation to send solicitations, information or advertisements to other subscribers. It will be considered a violation of rules if a subscriber sends unsolicited advertisements or information of a commercial nature to other subscribers.

Personally I will exempt myself from this. If you have a product to sell and you wish for me to know about it with possibility of it being added to my web page or posted to the list, that is fine, provided it is infrequent and if I ask for such mailing to stop it ceases.

If I get a complaint it will be considered the same as any complaint and action may include removal from the list. Count of infractions before removal will be up to the Panel of List Owners and personally I will take a more strict stand against corporate subscribers than I do social subscribers.

This policy is not intended to offend anyone, it is meant to address previous complaints from subscribers who wished to know the standing concerning advertising, commercial solicitation on the list. I hope it makes regular subscribers realize that while I'm letting these commercial subscribers on the list, it is not an open door to flood the list or other subscriber's mailboxes with advertisements.

I've had complaints before about people pushing products they have a financial interest in. But I've never wanted to close off people's availability to a resource. And I've always hoped and expected that those with such an interest would realize and keep advertisements to a minimum and just provide information when people ask.

This is a much more liberal policy than many other listowners have adopted.

Rule, Listowner, Panel and Censorship Discussion

Listowners have a right to set rules for participation in their list. They also have a right to enforce those rules. In fact it has been described as one of the responsibilities of a Listowner at St. Johns.

If everyone was considerate of everyone else's feelings and spoke politely to each other and didn't try to evoke responses using sarcasm, name calling and flaming there wouldn't be a need for rules and enforcement. Since instances on this list have shown the need to create rules, methods of enforcement have also been needed.

It is further stated that these rules are not for public list debate, or criticism. Further criticism of the Panel or the host site, even if they are warranted are no longer allowed. If you have issues with the Panel or the rules, address them strictly to the Panel via email directly to one of the Panel members.

If you have complaints about the host site you can figure out who to address them to there.

This site was gracious enough to allow, and continues to allow this list, which consumes considerable resources. Nothing made them do it and they have no responsibility beyond that, but we also have to abide by their rules.

Complaint Handling

How to Lodge A complaint

If you feel that someone has broken these rules or you have taken offense at something someone has said **DO NOT POST IT TO THE LIST. SEND YOUR COMPLAINT TO THE PANEL (ONE OF THE PANEL OF LISTOWNERS)**. If you wish to send a copy of your letter to the panel to the poster of the offending message that is up to you. **YOU DO NOT HAVE TO BE THE OFFENDED PARTY TO LODGE A COMPLAINT, ANYONE CAN LODGE A COMPLAINT ON BEHALF OF ANYONE ELSE.**

In your mail to the Panel, you need to show specifically the post that broke a rule and which rule it broke. This means actually forwarding a copy of the post in your email to the Panel, and including the text of the rule (either full text from this publication or from the brief one posted weekly), and then identifying how you feel the rules were broken.

The Panel member that receives the email will accept it and notify the sender of any formatting changes that may be needed and after the original sender approves of the format will forward it to the rest of the Panel members. This should happen within 1 day, allowing for the fact that all panel members may not read their email after normal business hours (and some may not be in your time zone), and some do not have access to email during the weekends or holidays.

When all Panel members have read the complaint one of the Panel members will email the poster advising them that The Panel have received a complaint about one of their posts. This notice will include the post, the rule that was broken and the interpretation of how that rule was broken.

The author of the offending post may discuss with listowners their side of the picture. However keep in mind that if you are saying something bad about the offended party you will be considered in the wrong.

At that time the Panel will discuss the situation via email and attempt to decide on appropriate action. The decision if the post is or is not a violation will be based on a majority of the votes of the Panel (ie. 3 of 4). If there is a tie vote the Panel will decide on a method of resolving the tie.

After a complaint is 90 days old, if no further problems have arisen the complaint is considered closed and the complaint count would start again at 0.

Banned members may rejoin after one year, provided they can show a willingness to abide by rules and not repeat what happened to cause their being banned.

Penalties

Most offenses not considered extremely grave will result in a warning message not to repeat the offense, if the Panel agrees that the post was offensive.

A subsequent offense if it appears to be non-intentional and occurs at a time not less than 90 days from the previous offense will result in a second warning, with the notice that this will be the last notice. If you receive a second notice and are having problems understanding why something is wrong please contact someone from the Panel and they will discuss it via email with you off-line. We realize some people may not realize certain things can be offensive, but to remain on the list you have to make an effort to learn how they are offensive and make an effort to correct the offense.

The third offense will result in removal from the list.

In the case of Grave offenses such as extremely vicious personal attacks of another subscriber with no remorse or attempt to apologize will result in an immediate removal from the list with no prior warning. However it will still be a general consensus of the Panel.

In some instances where a subscriber has posted something significantly beligerent, the subscriber may be put "NOPOST" until the problem is decided. During that time the subscriber will not be allowed to post.

If a member of the Panel sees a post that they feel is a breach of the rules they may initiate this process on their own, but it still must be handled the same, it must first go to all other Panel Members, a notice must be sent to the author of the offending post and the action must be by decision of the entire Panel, not just their own.

What happens if I post my complaint to the list?

Posting of a complaint to the open list is very likely to start a flame war or discussion about a fellow subscriber, therefore it is a direct violation of the rules. In that matter it will cause a legitimate complaint to be lodged against you.

Ban On Discussing A Banned Subscriber

Public Discussion of a banned member will not be allowed. That person has a right to be a part of the discussion. IF YOU WISH TO OFFER YOUR SUPPORT OF THAT PERSON SEE THE NEXT SECTION.

Supporting a Banned Subscriber

It is my opinion that Panels will sometimes make a mistake. Therefore I am not going to ban reasonable discussion with the Panel by subscribers offline, that is if you wish to support someone who has been banned, email the Panel describing why you think this person should not have been

removed. The only additional content to add here is that if they've broken the rules and shown no intention of correcting their behavior or refraining from future offenses of the same nature, the decision will most likely stand.

THIS DOES NOT MEAN THAT ANYTIME YOU DISAGREE WITH THE PANELS DECISION YOU CAN EMAIL THEM INCESSANTLY OR TREAT THE PANEL MEMBERS IN ANY MANNER BANNED BY THESE RULES FOR ANY SUBSCRIBER. THE PANEL MEMBERS ARE ALSO SUBSCRIBERS AND HAVE THE SAME RIGHTS UNDER THESE RULES.

If you wish to state a point or discuss a decision with the Panel it must be done in a decent respectful manner. If this discussion turns into a berating of the Panel, the discussion will be considered a violation of the rules.

All of us deserve respectful meaningful correspondance and there is no reason anyone on this list, subscriber or Panel Member should be expected to put up with anger, name calling or badgering by a subscriber. The Panel members all were volunteers who were approved by the majority of the population of this list that felt it in their interest to vote.

If you don't like the way the Panel operates or you don't like the rules, you are free to unsubscribe and seek out another list more suitable to your taste. There are others out there, some are more tolerant but most won't be.

Requests - Not Rules

The following are included due to a need, however they are not rules, actions will not be taken against people who may not do as requested. The request is due mainly to disk space limitations on the server at St. Johns where this list resides and as a common courtesy to others.

1. Please do not include large quotes when replying to posts, include only what is needed to show what you are responding to.
2. Please, if possible send "me too", "Thanks" and "good ideas" to the individual posters rather than the list, unless some subscriber has asked for a count for purposes of gathering statistics for their use. Another incident that would be ok would be in the case of where the Panel has asked for a readership opinion on some topic.
3. Please refrain from posting "repeat documents" on a regular basis. Exceptions to this would be FAQs relating to disability issues, these rules, the List FAQ, and related notices. Please keep these brief and to the point.
4. If you have a special interest please consider creating a web page for this information. Then when you add documents or information post a notice of what you have added and the reference to your page as well as a brief description of what the document is about. I know much information gets posted on here that has a wide audience, but some of it is of use to a limited number of subscribers and yet takes up alot of space, however if you don't have web capabilities we recognize that shortfall. You could even ask for suggestions of sites to set such a page up.
5. Please try to keep to the topic of disabilities and family experiences somewhat. However with

such a serious topic occasional off-topic items and humor are often a needed respite from the seriousness. Also try to really figure out if it's possible that what appears off topic to you might be directly related to disability for another person.

6. If you are going to send a joke please include in the subject line something such as "Subject: Jokes: Joke title".
7. If you are going to send something not directly related to autism lets put something in the subject line such as "Subject: Non-Autism: Poor Roads In New York" or "Subject: Off-topic: I wish I would win the lottery!". This is a nice convenience for people who are spending money trying to keep up to autism issues by reading this newsgroup.

Summarized Rules

To summarize the above:

1. Posting is a privilege not a right
2. No ridicule of another subscriber or The Panel.
3. No sarcasm directed against another subscriber or The Panel.
4. No name calling.
5. No personal attacks of any other subscriber or The Panel.
6. The only banned topic at this time is Abortion. (Subject to change!)
7. Stick to Discussion Guidelines while discussing anything.
8. No open or public posting calling for someone's removal (see above for how to handle complaints)
9. No open or public posting of complaints about a type or subject of postings (see above for how to handle complaints)
10. No open or public posting of discussion regarding a banned member. (see above for how to support a banned member)

ME-LIST MEMBER GUIDELINES

WHO MAY JOIN?

Both parents and professionals are welcome to join the me-list. However, in circumstances where a problem arises between parent(s) on the list and professional(s) on the list, the policy will be to allow parents to remain as list members and to remove the professionals involved. This policy is designed to keep controversy on the list to a minimum. The focus of the me-list is meant to be constructive discussion about ABA programs and related issues and constructive problem- solving for individual members - not controversial argument between members. Removal of professionals from list subscription should not be interpreted as any statement about them. It is just as likely that the parent was the problem and not the professional! However, I do not have the time or inclination to sort out such matters and will simply keep to the policy set forth above.

CONFIDENTIALITY

This is a confidential list. Please do not forward posts from this list to another list or to another person without the permission of the original author of the post involved and of anyone else mentioned in that post. You may inform others who you feel may benefit from joining the me-list of its existence. You may also pass general information from the list on to others who may benefit from this information, provided you remove any specific names or other identifying information.

WHO OWNS MATERIAL POSTED TO THE LIST?

Even a lawyer could not answer this one! BUT please NOTE: membership on the me-list implies that you agree to consider the original author of a post to be the copyright owner and that you will not publicly distribute or publish material from the list without the express permission of the original author.

LIST COURTESY

Please observe the following courtesies:

a) Do not post simple "Thankyou", "I liked your post", "Could you send me that pamphlet you spoke about?" and similar messages to the list. These messages are meaningful only to the person to whom you are speaking and therefore should be sent directly to that person. If you do not know how to figure out the email address of the original sender of me-list mail, read the header carefully and try hard to figure it out. Ask technical service at your internet provider to help you. But please do not send personal messages to the entire list simply because you don't know how to do this. The list is

limited to 50 messages per day and too many personal messages cause it to reach this limit too often.

b) Please append your email address to the end of your messages. This will help people figure out who they should reply to if they wish to send a personal reply. Replies that have wider relevance can, of course, be sent to the me-list address.

c) Please make sure that the subject lines of your posts accurately reflect the subject matter in your posts. This helps those of us who do not have time to read all of the posts choose those which are relevant to us.

d) The subject line "*****ALL MEMBERS READ THIS*****" (or any similar variation) IS RESERVED FOR USE BY ME. If everyone starts using it, everyone will start ignoring it. I need a way to communicate with everyone. Please do not use this subject line and please read anything that has this subject line.

e) Please do not go on vacation without setting your account to nomail (see the FAQ sheet for info on how to do this).

f) Please do not let your internet subscription lapse without first unsubscribing from the list.

g) No flames - on or off the list. If you have a problem with another subscriber, address your problem to me and see if I can resolve it peacably. We all have enough to worry about without receiving hate mail from numerous other list members complaining about something we have said on the list. Remember - something that seems fairly innocuous to you might seem unbearable to a parent whose stress level is already near the breaking point.

h) Comments about non-ABA therapies are welcome on the list, but prolonged discussions of such therapies should be posted to the VENT list or the St Johns' Autism list.

i) If you write to me, don't expect a fast reply...give me at least a week before bombarding me with repeated requests for whatever it is you want.

j) All list members will be expected to maintain their own accounts...i.e. changing your account to digest, repro, nomail, mail as appropriate. If you ask me to do something that you can do, you may simply receive a copy of the FAQ in return. With about 2000 members, there is no way that I can continue doing work for all of you.

WHAT IS APPROPRIATE TO POST TO THE LIST?

Appropriate material to post to the list includes the following:

1) any information that you think might be useful to others - everything from notes you may have taken at a recent conference to the name and number of a companies selling materials useful for ABA programs

2) any questions you may have that someone else on the list may be able to help you with

- 3) replies to questions or requests for information posted by others
 - 4) details of individual programs or of the progress of children in ABA programs
 - 3) limited information or information requests on non-ABA topics - but please note that long discussions of non-ABA material should be pursued on the VENT list, not the me-list. If such discussions develop on the me-list I will send a post to the list requesting that they be moved to the VENT list. Failure of members to abide by such a request will cause them to be placed on review status.
-

WHAT IS INAPPROPRIATE TO POST TO THE LIST?

Inappropriate material includes:

- 1) private notes to one other member - such as thankyou notes - these should be sent privately.
 - 2) opinions about non-ABA therapies: information or questions about non-ABA therapies is OK, but prolonged debate about the relative merits of these other therapies should be sent to the VENT list.
 - 3) Harsh criticisms of material posted by other members. Constructive disagreement on technical points of ABA, or differing opinions on quality of materials, consultants etc is OK, but overly harsh criticisms are not welcome on the list. If you are upset by a post, please just ignore it.
 - 4) Criticism of ABA providers, consultants and other professionals in the field. Constructive information is welcome, but libelous criticism is not. If you feel you know something particularly bad about a provider and wish to spread the word, invite individual list members to email you privately about the issue.
 - 5) Your opinions of the appropriateness of someone else's posts. The final word on what is and is not appropriate for the list is mine and individual members should not make comments on the list regarding appropriateness or inappropriateness of anything posted to the list.
-

Suggestions:

If you have any suggestions about additional information that should be on this page, please send them to me: rallen@iupui.edu

[Return to the ME-LIST home page](http://www2.addr.com/~me-list/mlguidelines.html)

HOW TO OPERATE YOUR ME-LIST SUBSCRIPTION

B**THIS PAGE!!**

Top**addressed on this page:**

[What is an email list](#)
[How to get on the me-list](#)
[How to get off the me-list](#)
[Individual postings versus digest format](#)
[How to change from digest format to individual postings](#)
[How to change from individual postings to digest format](#)
[How to temporarily stop receiving list mail](#)
[How to start your mail again after temporarily suspending it](#)
[What to do if you suddenly stop receiving mail from the list](#)
[How to send mail to the list](#)
[What to do if you are receiving mail from the list, but cannot send mail to the list](#)
[How to receive a copy of messages you send to the list](#)
[The difference between the list address and the listserv address](#)
[What to do if you change your email address](#)
[How to search the me-list archives](#)
[If you have a problem not mentioned here...](#)
[Suggestions...](#)

Wh**is an email list**

An email list works like this: any number of people join the list - i.e. become members. All members are given the privilege of sending mail to a central address [REDACTED]. Any mail sent to that address will be automatically sent out to all members of the list. So if you post a message to the list, all members will receive a copy. Members can then reply either directly to you, or to the list - either way you will receive a copy of all replies. Everything is done via email. The me-list currently generates 20-50 messages a day. These can be received either individually as they are posted to the list, or in a "digest" - a once/twice-a-day concatenation of all messages sent to the list that day.

How to get on the me-list

Send an email message to: [REDACTED]

Your message should have the words "subscribe to me-list" in the subject line and the following in

the message part:

- 1) a clear statement that you wish to join the me-list
 - 2) if you are the parent (or close relative) of a child with autism, clearly say so.
 - 3) if you are **not** the parent (or close relative) of a child with autism, state a reason for wishing to join the list and also give the following information:
 - your name
 - the organization or school system that you work for
 - the location of the organization or school system that you work for
 - your position in that organization or school system
 - 4) clearly indicate whether you want to receive the list as individual postings or in digest format (see below).
-

How to get OFF the me-list

To get off the me-list, just send the following message (NOTE - this must be in the MESSAGE part of your email - NOT in the subject line - leave the subject line blank):

unsubscribe me-list

to the listserv address:

listserv@iupui.edu

You should receive confirmation from the listserv that you have been removed from the list

Individual postings versus digest format

Approximately 30-50 messages are generated on the me-list every day. As a member, you can receive these messages in one of two alternative formats - as individual postings or as "digests".

Individual postings - if you choose this format, you will receive each message as it is sent to the list - i.e. you will receive 35-50 individual messages each day.

Advantages of this format - easier to read messages, easier to save and print specific messages and discard others.

Disadvantages of this format - if you don't read your mail often enough you will end up with hundreds of messages to wade through; your mailbox may overflow more rapidly; if you use compuserve (which charges on a per message basis) it will be expensive.

Digest format - if you use this format, you will be sent 2-3 "digests" per day. Each digest contains 5-20 messages concatenated together. You will still receive all of the same information as you would if you were receiving individualized postings - but you receive it in a small number of discrete packets

of information.

Advantages of this format - less clutter in your mailbox, easier to deal with if you don't read your mail often, may be cheaper

Disadvantages of this format - may be harder to download (depends on which internet provider/software you use), may be more difficult to selectively save/print certain specific messages (again, depending on your software/hardware).

The default on the me-list is the digest format - i.e. unless you specifically request otherwise in your subscription request, you will receive postings in digest format. However, you can switch from one format to another whenever you wish - see below:

How to change from digest format to individual postings

If you are receiving mail from the list in digest format and wish to receive mail as individual postings, simply send the following message (NOTE - this must be in the MESSAGE part of your email - NOT in the subject line - leave the subject line blank):

set me-list mail

to the listserv address:

listserv@iupui.edu

You should receive confirmation from the listserv that your subscription has been changed.

How to change from individual postings to digest format

If you are receiving mail from the list as individual postings and wish to receive mail as digests, simply send the following message (NOTE - this must be in the MESSAGE part of your email - NOT in the subject line - leave the subject line blank):

set me-list digest

to the listserv address:

listserv@iupui.edu

You should receive confirmation from the listserv that your subscription has been changed.

How to temporarily stop receiving list mail

If you are going away for a vacation or for some other reason will be unable to read your list mail for

a while, you will need to temporarily suspend your mail. If you do not do this, your mailbox may overflow with unread mail. This will cause error messages to bounce back to me each time the list tries to send anything to you and finds your mailbox full. On an average weekend, I accumulate over a hundred such error messages and I get tired of constantly deleting them. SO, please be responsible for your me-list account and set it to nomail whenever you won't be reading your mail at least 1x/week.

To temporarily stop receiving mail, simply send the following message (NOTE - this must be in the MESSAGE part of your email - NOT in the subject line - leave the subject line blank):

set me-list nomail

to the listserv address:

listserv@iupui.edu

You should receive confirmation from the listserv that your subscription has been changed.

NOTE: you must NOT hyphenate the word "nomail" - it is ONE WORD.

How to start your mail again after temporarily suspending it

To start your mail again, send one of the following commands: (NOTE - this must be in the MESSAGE part of your email - NOT in the subject line - leave the subject line blank):

EITHER:

set me-list mail

OR

set me-list digest

(depending on whether you want individual postings or digests, respectively - see above)

to the listserv address:

listserv@iupui.edu

You should receive confirmation from the listserv that your subscription has been changed.

What to do if you suddenly stop receiving mail from the list

If you suddenly stop receiving mail from the list, the most likely reason is that your mailbox overflowed because you were not reading or deleting your mail regularly enough. If this happens, your account is automatically set to nomail (see above). In order to correct this, send one of the

following commands: (NOTE - this must be in the MESSAGE part of your email - NOT in the subject line - leave the subject line blank):

EITHER:

set me-list mail

OR

set me-list digest

(depending on whether you want individual postings or digests, respectively - see above)

to the listserv address:

[REDACTED]

You should receive confirmation from the listserv that your subscription has been changed.

IF THIS DOES NOT WORK...i.e. if you still are not receiving mail after doing this, then it may just be that the list is held. Wait at least 2 days and if there is still no mail, contact me at [REDACTED]

How to send mail to the list

You send mail to the list in the exact same way as you send email to another person. Simply address it to:

[REDACTED]

DO NOT use the REPLY feature of your email software to send mail to the list. This usually results in a copy of the message that you are replying to being sent to the list - again. There is no need for this - it just takes up space on the list. Even worse are those people who receive the digest and hit the reply button - this causes the entire digest to be resent back to the list. Most software has the ability to reply without incorporating the original message in the reply. If you can figure out how to do this, fine. If you cannot, then NEVER use the "reply" function to post mail to the list. Rather, compose a message that clearly indicates what you are replying to and send it to the list (at the address above) as a NEW piece of mail - including the appropriate topic in the subject line.

What to do if you are receiving mail from the list, but cannot send mail to the list (i.e. the list rejects mail that you send to it)

Many people knowingly or unknowingly operate under more than one email address. In some cases, you are subscribed under an address such as:

[REDACTED]

but when you send mail, it is sent from a slightly different address, such as:

[REDACTED]

If this is the case, you may experience rejection of your mail to the list. The only solution is to forward a copy of the rejection notice that you receive from the list to me
[REDACTED] I should be able to solve the problem for you.

How to receive a copy of messages you send to the list

If you are receiving mail from the list as individual postings, you will not receive a copy of the mail you send to the list unless your account is set to repro mode. To do this, simply send the following message (NOTE - this must be in the MESSAGE part of your email - NOT in the subject line - leave the subject line blank):

set me-list repro

to the listserv address:

[REDACTED]

You should receive confirmation from the listserv that your subscription has been changed.

The difference between the list address and the listserv address

Any mail sent to the list address [REDACTED] is simply sent straight out to members. There's not much point telling the 2000 members that you want to set your account to digest is there? The listserv address [REDACTED] takes care of things like that - changes to your account and so on. Requests for all such changes go to the listserv address, while messages to the other members go to the list address.

What to do if you change your email address

If you change your email address, you need to send me a message clearly stating both your old address and your new address. Also tell me if you are receiving the list in digest format (if you don't tell me, I'll assume you are). I will then change the subscription for you.

How to search the me-list archives

All material sent to the me-list is archived. The archives can be searched by sending the appropriate command in the body (NOT the subject line) of an email message to the listserv address:

BASIC SEARCH COMMAND

The basic search command format is:

search xxx in me-list

(where xxx is the term you wish to search for).

You can also use simple Boolean expressions such as:

search iep AND school in me-list

search iep OR school in me-list

HOW TO GET MORE THAN 100 HITS

The search command above will return only the first 100 hits. In order to get the rest of the results of your search you will have to use either a date or a post# specification (all posts in the list archive are given a number - the first post was number 1, the second was number 2 and so on).

Thus, you would send something like the following:

search xxx in me-list from 97/03/01 to 97/04/01

search xxx in me-list since 97/03/01

search xxx in me-list until 96/12/28

note - date formats are yy/mm/dd.

search xxx in me-list.9182-

This last will only return hits after post 9182.

RESTRICTING A SEARCH TO POSTS FROM A CERTAIN PERSON

To find posts from a certain sender, use the format:

search * in me-list where sender contains xxx

where xxx is the sender you are searching for

RESTRICTING A SEARCH TO POSTS WITH A CERTAIN SUBJECT WORD

search * in me-list where subject contains iep

search * in me-list where subject sounds like iep

(This latter form helps to avoid missing hits because of spelling errors).

COMPOUND SEARCH REQUESTS

Search requests can contain more than one of the components above. Example:

search iep in me-list since 97/01/01 where sender contains rallen

SEARCHING FOR PHRASES

If you want to search for a certain phrase, put it in SINGLE quotes:

search 'extended school year' in me-list

This will return only those posts that contain the phrase extended school year. If you sent the following:

search extended school year in me-list

you would get all posts that contained the three words extended and school and year anywhere in the post.

NOTE - if you use double quotes:

search "extended school year" in me-list

you will get a CASE-SENSITIVE search - so you will not find a post in which the phrase is written as Extended school year, for example.

Remember, you can use booleans -

search 'extended school year' or esy in me-list

FOR MORE INFORMATION

For more detailed documentation on searching the archives, send the command

get listdb memo

to the listserv address:



If you have a problem not mentioned here...

Contact me at [REDACTED]

When you write to me, let me know what the problem is, when it began and send me a copy of any error messages you have received from the listserv.

Suggestions:

If you have any suggestions about additional information that should be on this page, please send them to me: [REDACTED]

Return
to the [ME-LIST home page](#)

APPENDIX C:

REQUEST SENT TO MS. ALLEN

LIST OWNER – ME LIST

RESPONSE RECEIVED AND MESSAGE SENT TO THE LIST

Dear Ms. Allen:

I am writing to ask a special request of your list serv. Before I ask, I would like to let you know that I am currently a member and a mom whose son was diagnosed about three years ago. Because of your list, my son has done very well.

The reason I am writing is I am currently working on my Masters in Education. I am writing my thesis on Autism. The first part of my thesis is what the "professionals" currently think about treatments towards Autism. The second part is what parents currently have to say about it. I have developed a short 15 question survey. I would not send the survey directly to the list. I would, with your permission, simply post a message to the list telling the parents the same thing that I have told you and then ask parents to contact me directly if they would be willing to participate. I would then send, either by direct mail or fax, the survey to complete and return to me. No names would ever be used.

I do know that your list serv is primarily for discrete trial interventions. I will be trying to obtain permission from other list serves as well.

In any event, I hope you can grant me this permission and if you have any questions regarding this project please contact me either at this email address or [REDACTED]

I look forward to hearing from you!

Carrie Tripp

Subj: **Re: Special Request from your List**
Date: 4/17/00 10:39:57 AM Eastern Daylight Time
From: [REDACTED] (RuthAllen)
Reply-to: [REDACTED]
To: [REDACTED]

Barrie,

I don't have any objection to your proposal to send information about your project to the me-list.

- Ruth Allen

----- Headers -----

Return-Path: <[REDACTED]>
Received: from [REDACTED] [172.31.33.225] by [REDACTED] (v70.20) with ESMTP; Mon, 17 Apr 2000 10:39:57 -0400
Received: from [REDACTED] [134.68.220.32] by [REDACTED] (v71.10) with ESMTP; Mon, 17 Apr 2000 10:39:30 -0400
Received: from iupui.edu ([134.68.79.12])
by iris.iupui.edu (8.9.3/8.9.3/1.2IUPUIPO) with ESMTP id JAA16893
for [REDACTED]; Mon, 17 Apr 2000 09:39:28 -0500 (EST)
Message-ID: <38FB3142.FB2732E2@iupui.edu>
Date: Mon, 17 Apr 2000 10:00:28 -0600
From: RuthAllen <[REDACTED]>
Reply-To: [REDACTED]
X-Mailer: Mozilla 4.7 (Macintosh; I; PPC)
MIME-Version: 1.0
To: [REDACTED]
Subject: Re: Special Request from your List
References: <62.2799f03.2629d442@aol.com>
Content-Type: text/plain; charset=iso-8859-1
Content-Transfer-Encoding: quoted-printable
X-MIME-Autoconverted: from 8bit to quoted-printable by [REDACTED] id JAA16893

Subj: **Need Help with Research Project**
Date: 4/20/00 5:10:28 PM Eastern Daylight Time
From: BFTripp
To: ME- [REDACTED]

Dear Me-Listers:

I am writing all of you to ask for help on a research project I am currently writing.

Before I explain the project, I want you all to know that I am a member of this list and am a parent of a child who is autistic. I have been "lurking" of almost three years and have gotten many great ideas from all of you and for that I thank you.

I am currently writing my masters thesis on Autism. At this point in the project I need help from parents. I want your opinions on the therapy you are using.

If you are interested in participating, please email me [REDACTED] [REDACTED] will than e-mail you the survey. It is fairly short (15 questions) and you can e-mail or fax it back to me. Of course no names will ever be used in the final project.

Thank you all for your help in advance.

Sincerely,
Barrie Tripp

APPENDIX D:

**COPY OF CORRESPONDENCE WITH
MR. KOPP – AUTISM LIST OWNER**

AOL.COM

Search AOL Mail for messages and attachments from AOL Mail



Exit AOL Mail

Close

Keep As New

Delete

Prev 17 of 17



Subj: Re: Request to send a message to your list

Date: Fri, 21 Apr 2000 8:25:56 AM Eastern Daylight Time

From: Ray Kopp [REDACTED]

To: [REDACTED]

☐ Include original in Reply

That is fine with me. What I would suggest is joining the list, temporarily if you do not wish to continue, but joining it long enough to get your request out and stay on for about a week in case people wish to ask you further questions. Quite often despite your request to have them reply to you directly they will reply to the list, that would give you and them a little longer to get together. If you didn't want to get the list in your mailbox, (which I can understand, over 100 messages a day), I would setup to nomail and then read the list via my digest page and search for your responses there. That page is:
<http://web.syr.edu/~rjkopp/autdigest.html>

Good luck,

Ray Kopp



Reply



Reply All



Forward

CO-OWNER: autism@maelstrom.stjohns.edu

Autism list FAQ: <http://web.syr.edu/~rjkopp/autismlistfaq.html>Autism List Rules: <http://web.syr.edu/~rjkopp/autismrules.html>Autism Digest Page: <http://web.syr.edu/~rjkopp/autdigest.html>

Form for joining/leaving/changing subscription parameters:

<http://web.syr.edu/~rjkopp/listjoin.html>Autism Page: <http://web.syr.edu/~rjkopp/autintro.html>Autism Links Page: <http://web.syr.edu/~rjkopp/autismlink.html>

Panel Of Listowners:autism-panel@hunter.apana.org.au

(this mails to all co-owners please use that address)

Ray Kopp, Linda Carlton, Carolyn Baird, Craig Thomas

>
 > Dear Mr. Kopp:
 >
 > Please allow me to introduce myself. My name is Barrie Tripp and I have a
 > son was diagnosed with Autism almost three years ago.
 >
 > I am writing to you to request permission to send a message to your list
 > serv
 > asking parents for their help.
 >
 > The request from parents would be about a research project I am currently
 > working on and not for my son. I am currently working on a Masters in
 > Education at Lynn University in Boca Raton, Florida and am writing my
 > thesis on Autism. At this point in the project, I need information from
 > parents to
 > determine what interventions they are using and their feelings about it.
 >
 > I, of course, would never use the names of parents in the final paper and
 > would not clog the list up with this. I would send a message briefly

> explaining the project and then ask them to contact me directly. I would
 > send them the survey and ask them to send it back to me either by fax or
 > email.
 >
 > If this meets with your approval please let me know at either this address
 or
 > at [REDACTED] If you need any additional information regarding this
 > project, please feel free to contact me at either address as well.
 >
 > I look forward to hearing from you.
 >
 > Sincerely,
 > Barrie Tripp

-----Headers-----

Return-Path: <[REDACTED]>
 Received: from [REDACTED] [172.18.150.3] by air-yd02.mail.aol.com (v70.20) with ESMTP; Fri, 21
 Apr 2000 08:25:56 -0400
 Received: from [REDACTED] [128.230.1.49] by
 rly-yd03.mx.aol.com (v71.10) with ESMTP; Fri, 21 Apr 2000 08:25:40
 -0400
 Received: from mailbox[REDACTED] [128.230.4.49] by
 syr.edu (8.9.3/8.9.3) with ESMTP id IAA20355 for [REDACTED];
 Fri, 21 Apr 2000 08:25:38 -0400 (EDT)
 Message-ID: <390048EA.EFFDF55C@mailbox.syr.edu>
 Date: Fri, 21 Apr 2000 08:26:18 -0400
 From: Ray Kopp <[REDACTED]>
 Organization: Syracuse University
 X-Mailer: Mozilla 4.51 [en] (Win95; I)
 X-Accept-Language: en
 MIME-Version: 1.0
 To: [REDACTED]
 Subject: Re: Request to send a message to your list
 References: <8e.3f8dc40.2630d33e@aol.com>
 Content-Type: text/plain; charset=us-ascii
 Content-Transfer-Encoding: 7bit

Close

Keep As New

Delete

Prev 17 of 17

Next

Help

AOL Hometown
 AOL Instant Messenger

AOL Mail
 New to Chat?

Find a Chat
 Community Directory

Download AOL
 Love@AOL

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 Privacy Policy

APPENDIX E:

COPY OF REQUEST SENT TO AUTISM LIST

Dear Lister:

I am writing all of you to ask for help on a research project I am currently writing.

Before I explain the project, I want you to know my son was diagnosed with Autism three years ago and this project was born with the desire to help other parents.

I am currently writing my masters thesis on Autism. At this point, I need help from other parents. I am trying to find out what your opinions are on the therapy you are using.

If you are interested in participating, please email me at [REDACTED] or [REDACTED]. I will then e-mail you the survey. It is fairly short and you will be able to either e-mail it back to me or fax. Of course no names will ever be used in the final project.

Thank you all for your help in advance.

Sincerely,
Barrie Tripp

APPENDIX F:

COPY OF QUESTIONS SUBMITTED TO PARENTS

SURVEY QUESTIONS

1. What is your child's diagnosis (PDD, Aspergers, etc)?
2. How old is your child currently?
3. How old was your child when he/she was diagnosed?
4. What is the primary type of therapeutic intervention you are currently using?
 - 4a. How long have you been using this type of therapy?
 - 4b. What is the main environment that your child is receiving this type of therapy?
 - 4c. If your child is receiving any type of services at home, please list approximately how many
Therapists you have working with the child and what is their background (I.e. College Students, high school students, family members, etc.).
5. Are you using any additional types of intervention (i.e. Diet, OT, ST, PT, and AIT) and for how long? If more than one, please list all.
6. How did you decide to use your primary type of therapy?
 - 6a. If you are using any additional types of therapy, how did you decide to use those as well?
7. From 1 being the lowest and 5 being the highest, please rate your satisfaction with the therapies being used and explain why?
8. If you have used different therapies in the past, please list which ones and what made you change?
9. Are you still researching different ways to help your child? If yes, what amount of time do you estimate you spend per month?
10. Are you receiving funding from a governmental agency or health insurer to help pay the costs associated with your child's intervention?
 - 10a. If yes, are the full costs covered?